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Factors that impact on adjustment in parents of children with a learning disability and/ or autism spectrum disorder

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ABSTRACT

Background Previous research has shown that parents of children with learning disabilities (LD) and/ or autism spectrum disorders (ASD) are more psychologically distressed than parents of neuro-typical children. The literature suggests that there is significant variation in the rates of maladjustment within this population, and the research into factors that influence parental adjustment is developing. This study aims to add to the research into the factors influencing adjustment to parenting a child with LD/ ASD. In particular, relatively under-researched concepts such as parental acceptance, time since diagnosis, and the influence of informational support to understand a child's needs, will be explored.

Method Two hundred and thirty five parents of children aged 4-19 participated in a questionnaire study, conducted through local additional support needs (ASN) schools and bases. Measures of psychological adjustment were gathered alongside measures of acceptance, positive gains, level of child's challenging behaviour and demographic information.

Results Along with other variables, psychological acceptance and was found to account for significant variance in parental adjustment. There were no observed relationships between adjustment and time since diagnosis, or level of informational support.

Conclusions The results have implications for the understanding of the role of acceptance in parent adjustment. Implications for intervention development and

future research directions are discussed, in addition to the methodological limits of the study.

Keywords Learning disability, autism spectrum disorders, parent adjustment, acceptance, informational support

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Acknowledgements

I would like to thank the parents who took the time to participate in my project. In completing this research, I have come to understand some of what these parents cope with on a daily basis, and I hope that this research will highlight their positivity, strength and resilience, while also facilitating discussion about the ways in which these families can best be supported.

I would like to thank North Lanarkshire Local Education Authority and the teachers who kindly facilitated data collection within their schools.

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PART 1. SYSTEMATIC REVIEW

Interventions to improve mental health in parents of children with a learning disability and/ or an autism spectrum disorder – a systematic review.

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Word count: 8,310

1. ABSTRACT

Background. Parents of children with a learning disability (LD) or autism spectrum disorder (ASD) are known to be more vulnerable to symptoms of depression, stress and anxiety than parents of neuro-typical children. Evaluations of interventions designed to improve the mental health of parents of children with LD/ ASD are varied in their focus, delivery, and intensity, and outcomes are mixed. Previous reviews have focused on specific types of intervention, or reviewed parent interventions for wider groups of developmental disabilities. Given the recent publication of national guidance on psychological therapies, a systematic review of the evidence for interventions to improve mental health symptoms of parents of children with LD and/ or ASD seems timely.

Method. A literature search for randomised controlled trials (RCTs) and controlled trials evaluating parent-focused interventions for improving mental health was conducted. Searches were carried out using electronic databases, and reference lists of key papers were searched.

Results. Fourteen studies met inclusion criteria. Meta-analysis was not possible due to the heterogeneity of included studies. The majority of the interventions reported significant improvements in mental health symptoms as compared to control groups. These studies included one RCT and two longitudinal studies. There was limited evidence to suggest beneficial effects of specific types of intervention. Parent skills training and psycho-education were well represented within the

sample, in addition to multi-component therapies, such as cognitive behaviour therapy (CBT).

Conclusions. Although evidence to support the use of short-term interventions with parents was found, methodological issues suggest caution in generalising results to a wider population. Further longitudinal research and RCTs are needed to strengthen the evidence base.

Keywords Learning Disability; autism spectrum disorder; parenting; stress; depression; anxiety; psycho-education; interventions; cognitive behaviour therapy

2. INTRODUCTION

Having a child with a learning disability (LD) or an autism spectrum disorder (ASD) can lead to a variety of emotional and psychological responses in parents. The research tells us that many families learn to cope with the ups and downs of parenting their child without significant difficulty (Frey *et al.* 1989), and recent research has focused on the positive impact of having a child with a learning disability, and on the successful strategies used by families to cope with additional demands (Trute *et al.* 2010). While this positive perspective represents a relevant and timely shift away from family deficit models of disability (Blacher *et al.* 2007), we must recognise that there are large variations in the levels of distress that these

families experience and that adjustment can vary over time and during certain periods in the child and family life cycle (Glidden & Schoolcraft 2003; Lin 2000).

It has been widely documented in the literature that parenting a child with a developmental or learning disability can be highly stressful (e.g. Byrne & Cunningham 1985; Olsson & Hwang 2008). These parents typically report poorer mental health outcomes than parents of neuro-typical children (Dyson 1993), and studies have shown that a high percentage fall within the clinical to borderline range for anxiety and depression (White & Hastings 2004). Within the wider adjustment literature, good mental health is conceptualised as a central construct of healthy parental adjustment. The increased incidence of mental health problems within this population of parents suggests a need for support and intervention. In addition to providing a service for improving the mental health of parents, the literature suggests that parental stress, mood and ability to cope are likely to affect parenting practice, impacting upon child emotional development and wellbeing (Deater-Deckard 2005; Al-Yagon 2007). Given the direct and indirect effect of parental mental health problems, it seems important that interventions are available to support this population.

There has been considerable research into the reasons for the increased vulnerability to mental ill health observed in parents of children with a developmental disability. Findings suggest that the influences on parental mental health and maladjustment are complex, multi-dimensional and variable within the population. Broadly speaking, the research into the factors that influence parental

adjustment to having a child with a developmental or learning disability fall into three categories: child characteristics, for example level of challenging behaviour (Quine & Pahl 1991), and communication skills (Frey *et al.* 1989). Family characteristics, for example marital satisfaction (Friedrich *et al.* 1985) and level of social support received (Frey *et al.* 1989). Thirdly, parental cognitive factors have been found to impact on adjustment e.g. parental appraisal (Trute *et al.* 2010) and acceptance (Lloyd & Hastings 2008).

In terms of child characteristics that impact on parental adjustment, Baker *et al.* (2003) found that intensity of a child's challenging behaviour is a better predictor of parenting stress and burden than type of disorder. Challenging behaviour is often observed in children with developmental disabilities (Emerson 2003), and there is an increasing evidence base for interventions to support parents to manage their child's behaviour. A number of behaviour management programmes have been designed for parents of children with LD/ ASD, following an applied behaviour analysis framework (e.g. Hudson *et al.* 2003; Wiggs & Stores 2001). Although some studies have suggested that the intensity of ABA interventions has a detrimental effect on maternal wellbeing (Schwichtenberg & Poehlmann 2007), there is an emerging evidence base for behavioural interventions in this population (Roberts *et al.* 2003).

With respect to alternative therapeutic interventions to support parents, much of the literature into parental cognitive factors has focused on CBT parenting interventions (Hastings & Beck 2004). These interventions focus on helping parents

to manage their own thoughts and beliefs about their parental role and their child. Other types of parent interventions researched in this field include stress management (Hudson *et al.* 2003), psycho-education (Bristol *et al.* 1993) and support groups (Shu & Lung 2005). This review will examine the interventions specifically designed to improve the mental health in parents of children with a learning disability and/ or autism, and will attempt to answer the following questions:

1. *How effective are interventions for addressing mental health in parents of children with LD/ASD?*
2. *What is the evidence for the efficacy of different intervention delivery (e.g. group, individually tailored, self help)?*
3. *What is the evidence for the efficacy of interventions based on different theoretical frameworks?*

3. METHOD

3.1. Inclusion and Exclusion Criteria

Criteria for inclusion and exclusion in this review, and the method of reporting results were informed by the guidance set out by the Centre for Research and Dissemination (CRD), at The University of York (www.york.ac.uk/inst/crd/).

3.1.1. Types of studies

Randomised controlled trials (RCTs), controlled trials, or studies that included a concurrent control or comparison group, that appeared in full in peer reviewed journals were included in this study. A scoping search of the literature revealed that there were very few RCTs specific to this topic area, therefore the author made the decision to widen the criteria to include some quasi-randomised and comparison studies. This limited the scope for meta-analysis, and therefore this review will include only narrative synthesis of the results. Observational studies, cohort studies and single subject, experimental designs were excluded due to problems generalising the findings. All studies included in this review included a pre and post intervention measure of parental stress, depression or anxiety. The review was limited to studies published in English.

3.1.2. Types of participants

Participants in this review were parents or key carers of children with a formally diagnosed LD and/or ASD, who participated in a form of parenting intervention. All diagnoses associated with LD were included in this study (e.g. Down Syndrome, Cerebral Palsy, Rett's Syndrome). Interventions that were delivered directly to children only were excluded. Some studies (e.g. Perry & Condillac 2010) reported on an intervention for the 'families' of children, but did not specify the participant's relationship to the child, therefore the review includes all carer participants in addition to parent participants. For simplicity, participants will henceforth be referred to as 'parents' with the understanding that this term is used to include key carers. In this study, 'children' were defined as individuals aged under 19 years.

There were no upper or lower age limits for parents, and no gender exclusions for parents or children. In order to be included, the parents that participated in the interventions must care for at least one child with LD and/ or ASD.

3.1.3. Types of intervention delivery and format

The review included all types of delivery (group based, individually delivered or self help). There was no upper or lower limit on the intensity or length of intervention. Psychological interventions that focused on changing parental cognitions or behaviour, with the aim of improving parental mental health were included. Studies that focused solely on changing child behaviour or enhancing child development, with no outcome measurement of parental stress, depression or anxiety were excluded. The review included interventions based on any psychologically based theoretical framework e.g. cognitive behaviour therapy, rational emotive therapy, and also included less theoretically based structures e.g. psycho-education and parent support groups.

3.1.4. Types of outcome measure

A criterion for inclusion in this review was that studies included a repeated measure (at least pre and post intervention) of parental mental health (stress, depression or anxiety). These criteria were chosen as they reflected the mental health outcome of the intervention. Other outcomes such as 'parenting efficacy' reflected a sense of parenting competence and skill, which may be related to psychological wellbeing. There are developments in the literature pertaining to a number of constructs that may represent parental 'adjustment', including parenting satisfaction (Whittingham

et al. 2009), parental locus of control (Wiggs & Stores 2001), quality of life (Feldman & Werner 2002) and parental self-efficacy (Raj & Salagame 2010). While the knowledge base is increasing, at the moment it is too diverse to compare all of these terms and outcomes meaningfully. As such, this review focuses on the mental health outcomes of interventions for parents. In order to preserve the theoretical and methodological integrity of the included studies, some relevant findings from child outcomes and non-mental health parent outcomes will be included. As this review was not intended as a meta-analysis, standardised and non-standardised outcome measures were included.

3.2 Search methods for identification of studies

3.2.1. Electronic searches

The following electronic databases were searched: PsycINFO (1860 to October 2012), Applied Social Sciences Index and Abstracts (1987 to October 2012), EMBASE (1980 to October 2012), Medline (1946 to October 2012). The Cochrane Library database was also searched to ensure that the topic of this review had not been recently conducted or planned. Two searches loosely fell within the topic of this review: a protocol for a review of psychological interventions for parents of children with chronic illness (Ecclestone *et al.* 2012), which did not focus on LD and/or ASD, and a review of parent training programmes for improving maternal psychosocial health (Barlow *et al.* 2003), which also had no LD and/ or ASD focus.

The search string ran as follows: [‘adjustment’ OR ‘emotional adjustment’ OR ‘social adjustment’ OR ‘adaptive behaviour’ OR ‘wellbeing’ OR ‘stress’ OR ‘chronic stress’ OR ‘psychological stress’ OR ‘stress reactions’ OR ‘caregiver burden’ OR ‘distress’ OR ‘stress management’ OR ‘quality of life’ OR ‘self esteem’ OR ‘self confidence’ OR ‘self efficacy’ OR ‘relationship satisfaction’ OR ‘satisfaction’ OR ‘marital satisfaction’ OR ‘life satisfaction’ OR ‘role satisfaction’ OR ‘need satisfaction’] AND [‘parent child relations’ OR ‘parenting’ OR ‘parent training’ OR ‘parental characteristics’ OR ‘parental expectations’ OR ‘parental role’ OR ‘parenting skills’ OR ‘parents’] AND [‘mental retardation’ OR ‘developmental disabilities’ OR ‘learning disabilities’ OR ‘autism’ OR ‘mental handicap’ OR ‘intellectual disability’] AND [‘intervention’ OR ‘early intervention’ OR ‘family intervention’ OR ‘group intervention’ OR ‘treatment’ OR ‘self instructional training’ OR ‘communication skills training’ OR ‘parent training’ OR ‘sensitivity training’ OR ‘training’ OR ‘support groups’].

The initial search was broad in its definition of parental ‘adjustment’. This highlighted the heterogeneity of the term ‘adjustment’ and the decision was subsequently made to limit the inclusion criteria to interventions focused on parental stress, depression or anxiety.

3.2.2. Searching other resources

The reference lists of selected studies were examined to identify additional studies for inclusion. The reference lists of published meta-analyses and systematic reviews were also examined for relevant papers.

3.3. Study selection

The process of study selection is detailed in Figure 1. and Table 1.

Figure 1. Flow chart of study selection

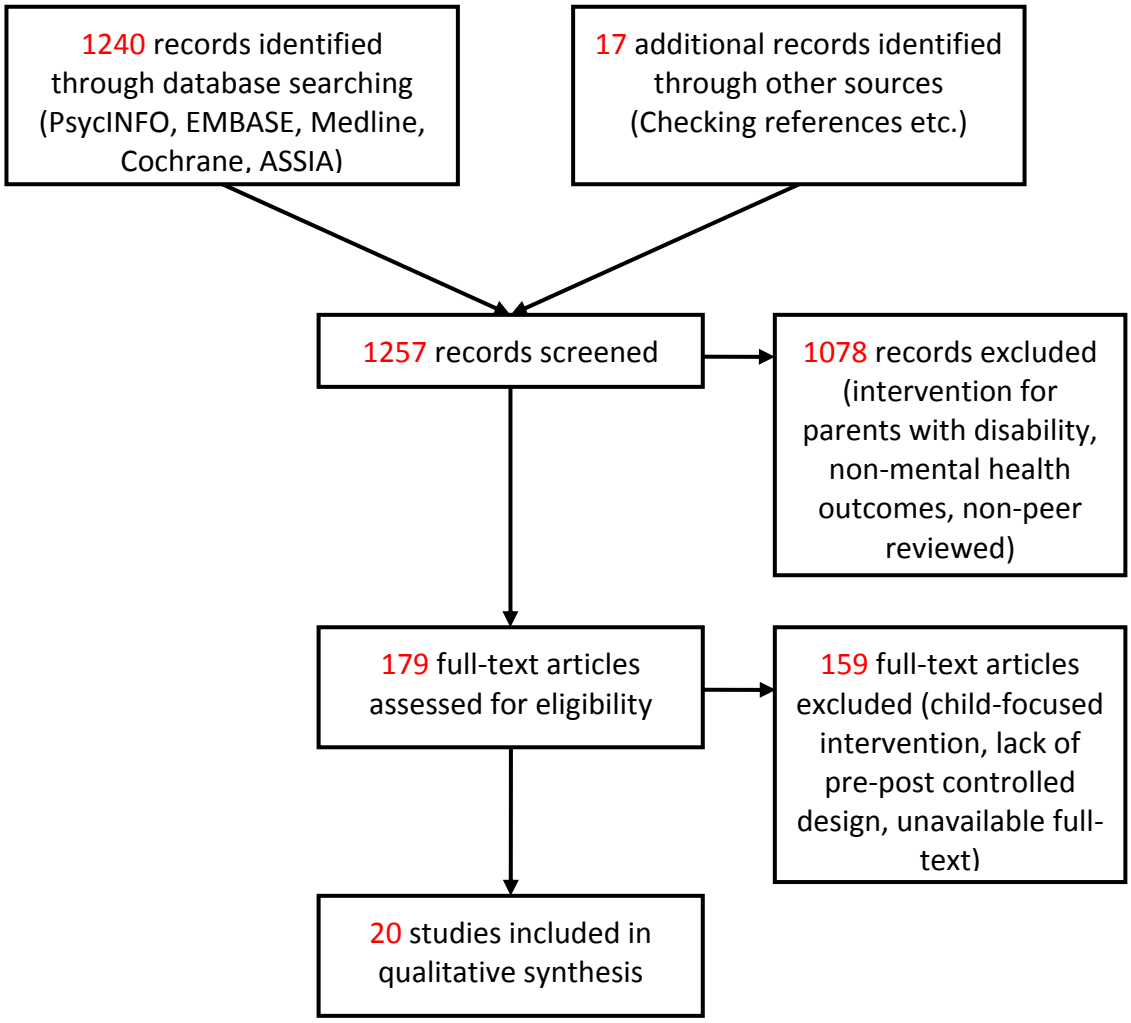


Table 1. Key characteristics of reviewed papers

TITLE	AUTHORS & YEAR	AIM	RESEARCH DESIGN	SAMPLE CHARACTERISTICS	PARENT MEASURES OF DEPRESSION/ ANXIETY/STRESS	OVERVIEW OF INTERVENTION(S)	CONCLUSIONS
Maternal depressive symptoms in autism: Response to psycho-educational intervention	Bristol *et al.* 1993	Compare impact of an individualised psycho-educational intervention on the depression symptoms of mothers of children with ASD as they go through the assessment and diagnosis process	Repeated measures, control group comparison design. Measures taken 2 wks before diagnosis, then 6 and 18 months later.	N= 28 (intervention=14, control=14) Children diagnosed with autism or 'related difficulties', aged 2-6 years.	Community Epidemiologic Depression Scale (CES-D)	**Intervention –**Bi weekly, timeframe not reported **Control –** No treatment	Significant reductions in depressive symptoms observed in intervention group, not for control, at 18 months post diagnosis. No significant effect of intervention at 6 month post diagnosis
A randomised trial of brief individual versus group parent training for behaviour problems in children with severe learning disabilities	Chadwick e*t al.* 2001	Compare a group based versus an individual based parent training intervention with concurrent teacher training, on reducing problem behaviour and enhancing parent wellbeing	Pre and post control group design. Measures repeated at 6 month follow up.	N=106 parents (group=48; individual=30; control=28). Children aged 4-11 years with severe LD	Parenting Stress Index (PSI)	**Intervention (group) –** 5x1.5-2hr sessions, once weekly **Intervention (individ)-** 5-7x1-2hr sessions, once fortnightly **Control –** waiting list	No statistically significant differences between groups in ratings of parental stress at pos-treatment. Statistically significant improvement in child behaviour for parents in individual intervention group only.
Superiority of group counselling to individual coaching for parents of children with learning	Danino & Shechtman 2012	Compare the effectiveness of process-oriented, counselling therapy for parents in both group and individual formats, with a waiting list	Pre and post control group design. Measures repeated at 6 month follow up (intervention groups only)	N=169 parents (group=93; individ=45; control=31). Children aged 6-18yrs, diagnosed LD.	Parenting Stress Index (PSI)	**Intervention (group) –** 12x1hr weekly sessions **Intervention (individ)-** 12x2hr weekly sessions **Control –** waiting list	Parent stress decreased significantly more for those in the group intervention than for individual intervention and control. Outcome stable at follow up. Both intervention groups

disabilities		control.					produced significantly better stress outcomes than the control group.
The effects of a coping skills training programme on the coping skills, helplessness and stress levels of mothers of children with autism	Erguner-Tekinalp & Akkok, 2004	Evaluate effects of a CBT coping skills training programme for mothers of children with ASD	Pre and post control group design. No follow up.	N=20 (intervention group=10; control=10) All children diagnosed with ASD, unknown when or how, or whether this was confirmed by authors. Children aged 11-19	Questionnaire on Resources and Stress - short-form (QRS-F)	**Intervention –** 8x1.5hr sessions. 2 sessions per week for 4 weeks **Control –** No treatment	Evidence that programme is useful for social supports and hopelessness, as compared to control group. No evidence that the programme impacts on stress, problem solving or avoidance.
The coping skills training programme for parents of children with developmental disabilities	Gammon & Rose, 1991	Examine impact of a CBT based skills training group programme for mothers of children with ASD	Pre and post control group design. No follow up.	N=42 (intervention group=24; control=18). Children had a developmental disability (inc. ADHD)	Profile of Mood States (POMS); Questionnaire on Resources and Stress (QRS-F)	**Intervention –** 10 x 2hr sessions weekly **Control –** No treatment	POMS score significantly superior for intervention group, but only on one subtest of seven. Significantly improved scores on QRS-F relative to control on 4 of 11 subtests, weak but positive support for improvement in stress.
The effect of rational-emotive parent educations on the stress of mothers of young children with Down Syndrome (DS)	Greaves, 1997	Assess the effectiveness of a rational-emotive parent therapy (REPE) on maternal stress, focusing on core irrational beliefs and links with stress, as compared to applied behaviour analysis (ABA)	Randomly assigned groups, pre-and post control and comparison group design. No follow up.	N=54 (REPE=21; ABA=17; control=16) All children attending centre of pre-school children with DS.	Parenting Stress Index (PSI); Stress Reaction Scale; The Feelings Scale; Profile of Mood States (POMS); Berger Anger and Guilt Scale.	**Intervention (REPE) –** 8 weekly sessions. No info on hours of input. **Intervention (ABA) –** 8 weekly sessions No info on hours on input **Control -** No-treatment	Significant reduction in stress and low mood scores for REPE group as compared to ABA/ control. Stress related to management and care of child reduced for all groups similarly. Reductions in anger/ guilt scores in both intervention groups but not control.

		treatment focusing on behavioural conditioning, extinction, reinforcement, and no-treatment control					
Effectiveness of a stress-relief initiative for primary caregivers of adolescents with intellectual disability	Hu *et al.* 2010	Compared mental health outcomes for a group based stress management programme for parents of young people with LD, versus self help literature only	Pre and post control/ comparison group design. No info on method of participant allocation	N= 77 (intervention=31; control=46). No info on adolescents' age range, diagnoses etc	Taiwanese Depression Questionnaire (TDQ)	**Intervention –** 2hr stress management workshop and self help booklet to study **Control –** self help booklet only	Significant improvement in mental health scores from pre to post for intervention group. Scores for booklet-only group showed increase in stress/ depression.
Evaluation of an intervention system for parents of children with intellectual disability (ID) and challenging behaviour	Hudson *et al.* 2003	Evaluate 'Signposts' manualised parent intervention across three modes of delivery. Intervention focus on positive parenting strategies, behaviour management and parental stress management	Semi-randomised, pre- and post control and comparison groups design. 4-6 month post intervention follow-up for intervention group only.	N= 115 mother-child dyads (Group support=46; telephone support=13; self-directed=29; control=27) All children diagnosed with ID, aged 4-19 years.	Depression, Anxiety and Stress Scale (DASS)	**Intervention (group) –** 6x2hr group meetings, fortnightly over 12 week period. **Intervention (telephone) –** Intervention literature delivered at fortnightly intervals. Fortnightly telephone support contact from a therapist (c.20mins) **Intervention (self-direct) –** Intervention literature delivered fortnightly with no support from telephone contact	Experimental groups had more favourable outcomes compared to control groups, no differences found between methods of intervention delivery. High attrition rate may have skewed results. Families with ASD most likely to drop out.

						Control – waiting list	
Treatment of children with autism: A RCT to evaluate a caregiver-based intervention programme in community day-care centres	Jocelyn *et al.* 1998	Evaluate group psycho-education and behaviour management intervention as compared to control group for group of parents with recently diagnosed autistic child	RCT pre- and post- control group design. No follow up outcome measures.	N = 35 parents (16 intervention; 19 control). Female=34 Male=1 Children aged 2-6years, recently diagnosed	Stress Arousal Checklist	**Intervention –** 12 weekly group sessions (seminars and consultations) **Control** – TAU	Improvements in parental knowledge of autism, no significant change in stress scores over time in intervention or control group.
The effects of a parent-focused intervention for children with a recent diagnosis of autism spectrum disorder on parenting stress and competence	Keen *et al.* 2010	Compare two types of psycho-education, parent training intervention (professionally supported group vs. self-directed video based group) on stress and sense of competence in parents of children who had received a diagnosis of ASD in past 6 months	Quasi-experimental, pre- and post control and comparison group design. 3 month post intervention follow-up	N= 39 'families' (17 professionally supported group; 22 self-directed video group). Female=39 Male= 37 Children 2-4 years, received ASD diagnosis in previous 6 months.	Parenting Stress Index (PSI) Parenting Sense of Competence (PSOC)	**Intervention (pro-supported group) –** Parent workshop (2 days) + 10x 1hr home visits. 6 weeks. **Intervention (self-directed) -** Instructional DVD with activity sheets. 6 weeks. **Control** – none	Concluded professionally supported intervention effective at reducing child-related parent stress, relative to the self-directed group for both mothers and fathers. Fathers showed significantly higher child-related stress scores on 3month post intervention follow-up than mothers.
Two-year follow-up of skills training with mothers of children with disabilities	Kirkham, 1993	Evaluate a life-skills, CBT focused programme, as compared to a parent support group for mothers of children with	Pre and post comparison group design. 2 year follow up. Multi-cohort sample	N=215 (intervention=143; control=72). 49% attrition overall. Children diagnosed with 'developmental	Questionnaire on Resources and Stress (QRS-F); Beck Depression Inventory (BDI)	**Intervention (life skills training) –** 9x2hr sessions, twice weekly for 5 weeks **Comparison (support group) –** met over	Life skills intervention effective in reducing depression post-intervention and showed significant reduction in depression at 6 month follow up, as compared to

		developmental disabilities		disabilities', aged 2-14yrs		same intervention period. Length of sessions not specified.	support group. No significant difference in reduction in stress levels between groups at post-test or follow-up
Group cognitive behavioural treatment for excessive parental self-blame and guilt	Nixon & Singer, 1993	Evaluate the effect of a CBT-based support group for parents for mothers of children with moderate to profound LD as compared to a no-treatment control	Pre and post control group design. No follow up.	N=34 (intervention=18; control=16). Children diagnosed with moderate to profound LD. Mean age 9.3 years	Beck Depression Inventory (BDI)	**Intervention –** 5x2hr sessions. No info on frequency. **Control** – waiting list	Significant difference in depression reduction between intervention and control groups.
Longitudinal effects of an early family intervention programme on the adaptation of parents of children with a disability	Pelchat *et al.* 1999	Assessing the effects of a psycho-dynamic, family systems inspired parent programme on the adaptation of parents to their child's disability (DS or cleft lip/ palate)	Longitudinal repeated measures (6, 12 and 18 months) control group design.	N=74 two-parent families (intervention group=33; control=41). All children had diagnoses of DS or cleft lip/palate and were aged 6 months at start of intervention.	Stress Appraisal Measure (SAM); Parenting Stress Index (PSI); Emotional Distress Index of the Quebec Health and Social Survey	**Intervention –** 6-8 meetings between nurse and family over 6 month period. **Control –** No treatment	Lower levels of stress, emotional distress, anxiety and depression in parents in intervention group. Generally maintained throughout the year long intervention and similar for mothers and fathers.
The TRE-ADD preschool parent training programme: Programme evaluation of an innovative service delivery model	Perry & Condillac, 2010	Assess effectiveness of parent training and psycho-educational group programme (TRE-ADD) as compared to two control groups of families receiving low or high intensity input	Pre and post control group design. Multi-cohort group administration. No follow up.	N=37 (TRE-ADD intervention=27; Low intensity control=5, High intensity control=5) Children aged 23mo-5.5yrs and diagnosed with either ASD or PDD-NOS	Questionnaire on Resources and Stress (QRS-F)	**Intervention –** 11x3hr sessions, delivered weekly over 11 weeks **Control 1-** Waiting list but receiving other input to manage behaviour **Control 2 –** waiting list receiving little-no	No significant difference in stress levels post-test for intervention or control groups. Parents reported feeling low confidence in ability to continue using skills learned after group.

		while on waiting list for parent training				alternative intervention	
Behavioural family intervention for children with developmental disabilities and behavioural problems	Roberts *et al.* 2006	Assessing impact of individually administered family intervention, using both clinic and home based sessions on parental stress	RCT, pre and post control group design. 6 month follow up for intervention group only.	N= 47 families (intervention=23, control=23). All children assessed as having an LD, only c.50% had a diagnosis e.g. DS, CP. Children aged 2-7 years.	Depression-Anxiety-Stress Scale (DASS)	**Intervention –**10 session programme. Optional extra modules. No details on time frame or intensity of programme **Control –** TAU	No significant effects of intervention on parental stress, but normative levels noted at pre-test. Anxiety/ Depression outcomes not reported.
A RCT of two early intervention programmes for young children with autism: Centre based with parent programme and home based	Roberts *et al*. 2011	Compares outcomes for two programmes – a centre-based manualised programme and a home based individualised programme, both focusing on positive parenting, behaviour management, psycho-education and support with a non-treatment waiting list control	RCT, pre and post group comparison. No follow-up. Multi-cohort group administration.	N=95 (home-based group=34; centre-based group=33, control=28) Children aged 2.5-5yrs, diagnosed with ASD, confirmed during study with ADOS.	Parenting Stress Index (PSI)	**Intervention (centre-based) –** 40x2hr sessions, delivered weekly for 40 weeks **Intervention (home-based) –** 20x2hr sessions, delivered fortnightly over 40 weeks **Control –** No treatment	Overall evidence for superiority of centre-based interventions for parents and children above home-based interventions. Neither type of intervention impacted significantly upon stress.
Caring for fathers and mothers of children with intellectual disability: A pilot study	Schultz *et al.* 1992	Evaluation of a programme for parents of children with ID, focusing on problem solving, psycho-education and developing	Pre and post control group design. No follow-up.	N=57 parents (intervention group=39; control=18) Children diagnosed with ASD/ CP/DS. 67% of intervention	Parent and Family Problems subscale of QRS-F; Impact of Events Scale.	**Intervention –** 6x2hr sessions, delivered weekly for 6 weeks **Control** – No treatment	Non-significant treatment effect on all subscales. Qualitative responses provide evidence in support of intervention, in terms of reported attitude change in parents.

		strengths, as compared to a control group		group 'undifferentiated'.			
The effect of a support group on the mental health and quality of life for mothers with autistic children	Shu & Lung , 2005	Comparing mental health outcomes of a semi-structured support group, introducing awareness of coping, stress, relationship issues and caring for a child with ASD with a no-treatment control	Quasi-experimental pre- post control group design. 1 month follow-up.	N=27 (Support group=8, control=19) All children diagnosed with autism by child psychiatrist	Chinese Health Questionnaire-30 (CHQ-30); World Health Organisation Quality of Life-BREF (Taiwan version)	**Intervention –** 10x90 min support group sessions, held weekly over 10 weeks. **Control –** Contacted and opted out of group. No other info.	No significant differences found between control and experimental group on CHQ-30 or WHO-QOL at pre-post or follow-up
The effectiveness of a parent-child interaction therapy for families of children on the autistic spectrum	Solomon *et al.* 2008	Evaluating an interaction therapy as compared to a matched-subjects control group for parents of children with ASD	Pre and post control group design. No follow up.	N=19 (Intervention=10; control=9). All children were male, aged 5-12, met criteria for ASD and clinically significant behaviour probs. No LD.	Parenting Stress Index (PSI)	**Intervention –** 12 sessions of parent training/ coaching **Control –** No information	No significant decrease in reports of parental stress between pre and post intervention. No significant reduction in child problem behaviours.
Effects on parental mental health of an education and skills training programme for parents of young children with autism: A RCT	Tonge *et al.* 2006	Assess the impact of a parent education and behaviour management programme (PEBM) on the mental health of parents of pre-school children with autism, as compared to	RCT, pre and post control and comparison group design, and 6 month follow up for all groups	N=105 (PEBM= 35; PEC=35; Control=35) Children were aged 2.5-5yrs, diagnosed with autism using ADI-R, screened by researcher to ensure validity	General Health Questionnaire-28 (GHD-28); Parenting Stress Thermometer; Family Assessment Device (FAD)	**Intervention (PEBM) –** 10x90min group sessions, alternated with 10x60min individual sessions over 20 week period. **Intervention (PEC) –** 10x90min group sessions, alternated with 10x60min	Both PEBM and PEC interventions led to significant improvements in GHQ-28 scores as compared to control group. No statistical evidence to support superiority of one intervention over another at post-test or 6-month follow-up.

		concurrent manual-based non-directive parent education and counselling (PEC) group, and no-treatment control				individual sessions over 20 week period. **Control -** TAU	

3.3.1. Methodological quality of included studies

Standardised approaches to quality criteria for studies included in a systematic review are inherently complicated. Due to the variation in methodology, and also inclusion criteria, specific quality criteria are often defined a priori. The quality criteria for this study were adapted from recommendations by the Centre for Reviews and Dissemination (CRD 2008). These criteria were then assessed using ratings as laid out in the Scottish Intercollegiate Guidance Network guideline on assessing methodological quality of RCTs (SIGN 2011). Table 1 details the characteristics of the reviewed papers, from which it can be seen that only three meet methodological criteria for RCT. As laid out in the inclusion/ exclusion criteria, this review did not restrict studies based on randomisation, however it was felt that the SIGN guidelines were applicable to less methodologically robust studies. A summary of the methodological quality of the studies is detailed in table 2.

Table 2. Methodological quality criteria of included studies (ranked in order of quality)

STUDY	a)RANDOMISATION	b) BASELINE ASSESSED	c) CONFOUNDS CONTROLLED	d) OUTCOME MEASURES	e) QUALITY OF REPORTING	f) ATTRITION	g) POWER	h) GENERALIZABILITY	i) QUALITY SCORE /16
Kirkham, 1993	Poorly addressed	Well covered	Well covered	Well covered	Well covered	Adequately addressed	Not reported	Adequately addressed	10
Roberts *et al.* 2011	Well covered	Adequately addressed	Adequately addressed	Adequately addressed	Well covered	Poorly addressed	Adequately addressed	Adequately addressed	9
Tonge *et al.* 2006	Well covered	Adequately addressed	Poorly addressed	Well covered	Well covered	Well covered	Not reported	Poorly addressed	9
Keen *et al.* 2010	Poorly addressed	Well covered	Poorly addressed	Adequately addressed	Well covered	Well covered	Not reported	Poorly addressed	7
Roberts *et al.* 2006	Adequately addressed	Adequately addressed	Poorly addressed	Well covered	Poorly addressed	Well controlled	Not reported	Poorly addressed	6
Schultz *et al.* 1992	Not reported	Well covered	Poorly addressed	Well covered	Well covered	Poorly addressed	Not reported	Poorly addressed	6
Danino & Shechtman, 2012	Poorly addressed	Well covered	Adequately addressed	Adequately addressed	Adequately addressed	Poorly addressed	Poorly addressed	Poorly addressed	5
Hudson *et al.* 2003	Poorly addressed	Not reported	Adequately addressed	Well covered	Well covered	Poorly addressed	Not reported	Poorly addressed	5
Jocelyn *et al.* 1998	Adequately addressed	Adequately addressed	Adequately addressed	Poorly addressed	Adequately addressed	Adequately addressed	Not reported	Poorly addressed	5
Nixon & Singer 1993	Poorly addressed	Adequately addressed	Adequately addressed	Adequately addressed	Well covered	Not reported	Not reported	Poorly addressed	5

Pelchat *et al.* 1999	Poorly addressed	Adequately addressed	Poorly addressed	Adequately addressed	Well covered	Adequately addressed	Not reported	Poorly addressed	5
Perry & Condillac, 2010	Not reported	Adequately addressed	Adequately addressed	Adequately addressed	Adequately addressed	Adequately addressed	Not reported	Poorly addressed	5
Shu & Lung 2005	Poorly addressed	Well covered	Poorly addressed	Adequately addressed	Adequately addressed	Not reported	Not reported	Poorly addressed	4
Bristol *et al.* 1993	Poorly addressed	Adequately addressed	Poorly addressed	Poorly addressed	Well covered	Not reported	Not reported	Poorly addressed	3
Chadwick *et al.* 2001	Poorly addressed	Adequately addressed	Poorly addressed	Adequately addressed	Adequately addressed	Poorly addressed	Not reported	Poorly addressed	3
Hu e*t al.* 2010	Poorly addressed	Poorly addressed	Poorly addressed	Adequately addressed	Adequately addressed	Adequately addressed	Not reported	Poorly addressed	3
Soloman *et al.* 2008	Poorly addressed	Poorly addressed	Adequately addressed	Adequately addressed	Adequately addressed	Not reported	Not reported	Poorly addressed	3
Erguner-Tekinalp & Akkok, 2004	Poorly addressed	Adequately addressed	Poorly addressed	Poorly addressed	Adequately addressed	Not reported	Not reported	Poorly addressed	2
Gammon & Rose, 1991	Poorly addressed	Not reported	Poorly addressed	Adequately addressed	Adequately addressed	Not reported	Not reported	Poorly addressed	2
Greaves, 1997	Poorly addressed	Not reported	Adequately addressed	Poorly addressed	Adequately addressed	Not reported	Not reported	Poorly addressed	2

a) Randomised assignment of participants to treatment group(s)

b) No significant differences between groups at pre-test

c) Effects seen at post-test/ follow up are products of intervention – other confounding variables are statistically controlled for and methods stated

d) Outcome measures suitable to study, authors recognising and stating validity and reliability

e) Non-selective outcome reporting, reducing reporting bias
f) Clear reporting on numbers failing to complete post-test/ follow-up measures in all groups, issues of missing data reported and methods explained
g) Power calculation is reported and adequate power achieved from sample
h) External validity of results
i) Quality score

3.3.2. Quality and risk of bias

From table 2, it can be seen that there are large variations in the methodological quality of studies reviewed. While the quality criteria do not allow direct comparison between studies, the criteria provide a framework from which to evaluate each study in context. The studies include three randomised controlled trials (Jocelyn *et al.* 1998; Roberts *et al.* 2011; Tonge *et al.* 2006), and seven studies that reported using randomised assignment of participants, but provided no detail about the randomisation method used (Erguner-Tekinalp & Akkok 2004; Gammon & Rose 1991; Greaves 1997; Kirkham 1993; Nixon & Singer, 1993; Schultz *et al.* 1992; Solomon *et al.* 2008). The remaining studies used alternative methods of assigning participants, including allowing participants to opt in to treatments (Danino & Shechtman, 2012; Shu & Lung 2005), or using cluster randomisation to assign participants based on proximity to clinics (Chadwick *et al.* 2001; Keen *et al.* 2010). Some studies did not report method of assigning participants (Erguner-Tekinalp & Akkok 2004; Hu *et al.* 2010). The overall lack of blinding and randomisation in the reviewed studies increases the risk of selection and allocation bias in these studies, and also increases the risk of demand characteristics on the part of the participants.

Only two studies reported power calculations. Roberts *et al.* (2011) narrowly failed to recruit the recommended number of participants based on their calculations. Danino and Shechtman (2012) did not retain a large enough sample at post intervention to produce adequate power. Sample sizes across studies varied from 215 (Kirkham 1993) to 20 (Erguner-Tekinalp & Akkok 2004). The accuracy of sample

size was also difficult to determine, as some studies quantified participants as 'families', as opposed to parents. The lack of reported effect size and power calculations meant that the effect of the intervention could not be reliably detected in the included studies.

Overall, the studies used valid outcome measures for stress, depression and anxiety, with good internal validity. There was some variation in the outcome measures used to evaluate parental stress, anxiety and depression across the studies, however the measures used were largely appropriate. Some studies used non-standardised scales, or adapted scales for the study (e.g. Greaves 1997). In the majority of cases, alpha coefficients were reported for the outcome measures used. The method of gathering outcome data was self report. Although this was standard across studies and therefore increases validity of comparison, it should be noted that self-report measures are subjective by nature, and may lead to unreliable accounts of current mental health.

4. RESULTS

4.1. How effective are interventions for improving mental health in parents of children with LD/ASD?

Of the studies rated highest on quality, three of the top six demonstrated positive outcomes for intervention (Keen *et al.* 2010; Kirkham 1993; Tonge *et al.* 2006). This indicates that the evidence for the efficacy of parent interventions is inconclusive. Ten of the studies reported no statistically significant effect of intervention on measures of mental health at post intervention (Chadwick *et al.* 2001; Erguner-

Tekinalp & Akkok 2004; Gammon & Rose 1991; Jocelyn *et al.* 1998; Perry & Condillac 2010; Roberts *et al.* 2006; Roberts *et al.* 2011; Schultz *et al.* 1992; Shu & Lung 2005; Solomon e*t al.* 2008). Some studies report mixed results, such as a reduction in depression but not stress (Kirkham 1993), or significant improvement in mental health at follow up that was not apparent upon intervention completion (Bristol *et al.* 1993).

Looking in more detail at the outcomes suggests that certain groups of participants may be most likely to benefit. The mental health outcomes for mothers and fathers also showed some variability. For example, the findings from Keen *et al.* (2010) indicate that fathers experience more child-related stress after intervention than mothers. This distinction is consistent with previous research demonstrating differences in sources of stress between parents (Hastings 2003; Hastings & Brown 2002; Hastings *et al.* 2005) however the authors recommend continued research into outcomes for fathers in order to make sense of these differences. It is noteworthy that only two studies (Keen *et al.* 2010; Pelchat *et al.* 1999) reported an equal gender split in their samples of parents. While the under-representation of fathers in these intervention studies is to be expected given the relatively recent research interest in fathers of children with LD/ ASD, this necessitates caution in broad generalisations about the benefit of interventions to 'parents' as opposed to mothers.

Interestingly, Kirkham *et al.* (1993) found that the parents that showed most improvement in parental satisfaction from the skills building group were single

mothers. While this is not a direct measure of mental health, the finding provides further support to the notion that different subsets of parents may benefit more or less from different interventions. In a similar vein, Tonge *et al.* (2006) found no overall effect of group on mental health outcomes, however interaction analysis demonstrated significant effect of group based on pre-test scores. This indicates that parents who scored highly on measures of psychological distress prior to intervention received most benefit, and this was maintained at six month follow-up. This finding suggests that level of pre-existing parental psychological distress may serve as a predictor of intervention outcome. While these differential findings for participant subgroups allows for comment on the universality of interventions for all parents, empirical conclusions are limited due to methodological issues such as lack of power calculations, randomisation and effect size.

Most studies reported analysis of demographic variables at baseline to ensure that intervention and control/ comparison groups were not significantly different, however few reported variance in pre-test scores, or used pre-test scores in correlation analysis with post test scores. This could result in invalid reporting, and also missed opportunities to determine any variance in the outcomes of interventions for particular subsets of participants. Failure to account for the impact of pre-test scores on post intervention outcomes reduces validity and may lead to type I and II errors. Additionally, a minority of studies reported demographic variability at post intervention to ensure attrition had not significantly altered the profile of the sample (Hudson *et al.* 2003; Kirkham 1993; Pelchat *et al.* 1999; Roberts *et al.* 2006). Studies that did compare pre and post intervention

demographic data found significant differences e.g. Hudson *et al.* (2003) found that families with a child with ASD were most likely to drop out of a group for families of children with intellectual disability. Methodological issues such as these increase the risk of invalid conclusions due to unrepresentative samples.

A minority of studies that focused on parents of children with LD/ ASD or developmental disability included conditions that would not meet diagnostic criteria e.g. 23 per cent of the overall sample in Kirkham's (1993) study listed the child's primary disability as language delay, visual/ hearing impairment or emotional disturbance, and Pelchat *et al.* (1999) included families of children with cleft lip/ palate. As these conditions are not necessarily associated with LD/ ASD, this has implications for the evidence base for interventions aimed at parents of children with LD/ ASD.

Although all the studies used pre and post outcome measurements, ten studies did not include a longitudinal or follow up measure (Erguner-Tekinalp & Akkok 2004; Gammon & Rose 1991; Greaves 1997; Hu *et al.* 2010; Jocelyn *et al.* 1998; Nixon & Singer, 1993; Perry & Condillac 2010; Roberts *et al.* 2011; Schultz *et al.* 1992; Solomon *et al.* 2008). Shu and Lung (2005) reported on one month follow up. Three of the six studies ranked highest in quality in this review included at least six month follow up (Kirkham *et al.* 1993; Roberts *et al.* 2006; Tonge *et al.* 2006). Keen *et al.* (2010) included three month follow up. Roberts *et al.* 2006 found no effect of intervention at post-test or follow up, while Keen *et al.* (2010), Kirkham *et al.* (1993) and Tonge *et al.* (2006) found that significant effect of intervention was maintained

at follow up. The lack of follow up measures limits the ability to comment on the longitudinal impact of any findings.

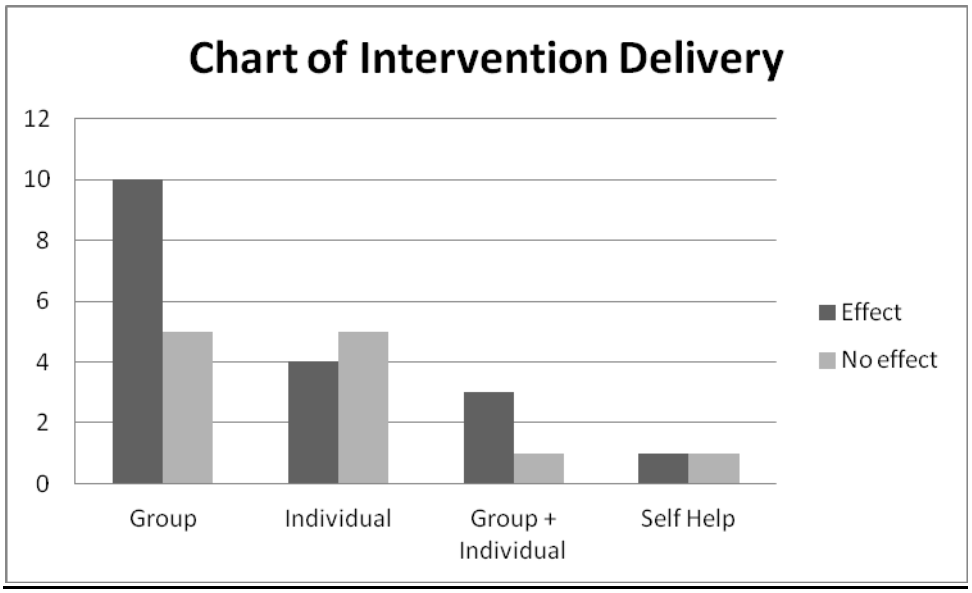
The methodological and reliability issues within these studies necessitates caution in interpretation and generalisation, however the overall theme from the studies reviewed indicates that parental intervention can lead to improvements in the mental health of parents of children with LD/ ASD. In addition to improving mental health outcomes, Kirkham (1993) also demonstrated significant improvements for parents in the skills building group in personal coping, parental communication skills and heightened satisfaction in the parent-child relationship, all of which were maintained for two years post intervention. These additional outcomes are likely to contribute to parental well-being, impacting on parental mental health. The relevance of these additional outcomes is supported by the findings of Trute *et al.* (2010), a study that provided support for the influence of cognitive processes such as coping, positive mood and positive appraisals as impacting upon stress and adjustment.

4.2. What is the evidence for the efficacy of different intervention delivery (e.g. group, individually tailored, self help)?

Of the studies showing positive mental health outcomes, the most highly rated in quality evaluated a five week CBT and skills training group (Kirkham 1993), a partially individualised 20 week CBT and skills training group (Tonge *et al.* 2006) and a partially individualised six week psycho-education and skills training group (Keen

et al. 2010). This lends support to the evidence base for short term interventions incorporating both group and individualised formats. Figure 2 illustrates the number of interventions delivered in each format.

Figure 2. Chart of intervention delivery



Most of the interventions were standardised parent training programmes, delivered in a group format with no focus on individualising the intervention (Erguner-Tekinalp & Akkok 2004; Gammon & Rose 1991; Greaves 1997; Hu *et al.* 2010; Hudson *et al.* 2003; Kirkham 1993; Nixon & Singer 1993; Schultz *et al.* 1992; Shu & Lung 2005; Tonge *et al.* 2006). In contrast, some of the interventions were individually tailored and involved some collaboration with the families (Bristol *et al.* 1993; Pelchat *et al.* 1999; Roberts *et al.* 2006). While this appears to be a minority, some sampling issues prevented other studies being fully evaluated e.g. Roberts *et al.* (2006) reported no reduction in stress symptoms after an individualised intervention for families of children with LD, however the baseline stress scores for

the sample were within the normal range. Overall, the individualised interventions were ranked lower in quality and demonstrated poor outcomes. Other interventions included a combination of group and individualised delivery (Keen *et al.* 2010; Perry & Condillac 2010; Roberts *et al.* 2011, Tonge *et al.* 2006). Keen *et al.* (2010) included home based sessions to ensure skills learned in the group were used effectively at home, while Hudson *et al.* (2003) provided written materials, which may have facilitated continued skill development at home, encouraging flexibility across settings. There were relatively few studies included in this review that evaluated combinations of group and individual intervention, however these studies were generally higher in quality and produced positive outcomes.

Five of the intervention descriptions explicitly stated a focus on parental self-care and stress management skills (Erguner-Tekinalp & Akkok 2004; Hudson *et al.* 2003; Kirkham 1993; Perry & Condillac 2010; Tonge *et al.* 2006). The outcomes from Hudson *et al.* (2003) show that those in the experimental groups improved in scores of confidence and felt that their needs were being met. Similarly, findings from Kirkham (1993) suggest that parents in the intervention group saw improvements in marital satisfaction, parent satisfaction and personal coping alongside improvements in depression scores. The findings in these studies suggest that parental mental health is mediated through the specific processes intrinsic to the intervention design, although further analysis would be required for confirmation of this hypothesis.

Of the studies that compared treatment groups, Keen *et al.* (2010) reported a significant effect of intervention type on child related stress when controlling for baseline, in a comparison of self directed and professionally supported interventions. The study concluded that professional support was most effective in supporting parents, and that information delivered to families via a DVD did not show the same advantages. This finding appears to lend support to the notion that peer and/ or therapist contact can go some way to improving parental mental health. Hudson *et al.* (2003) found no effect of intervention in their study, which compared group meetings with self directed interventions, some of which included regular telephone contact with a therapist. All three intervention types (group, self directed with telephone support, self directed with no telephone support) were found to be superior to the no-treatment control, but no intervention delivery was found to be more effective at alleviating mental health difficulties. While this appears to provide support in favour of minimum contact, cost effective intervention, it was noted by the authors that parents in the self directed groups were more likely to drop out of intervention. This high attrition rate, considered alongside the lack of statistical power in calculating sample size, and lack of randomisation reduces the reliability of the results.

In their RCT, Roberts *et al.* (2011) compared a centre based group, using a manualised parent training programme with a home based individualised programme with a no-treatment control. This study found that no intervention type was superior to another in terms of stress outcomes, however parent perceptions, coping skills, understanding and overall family quality of life improved significantly

more in the centre-based group as compared to the home-based group. The lack of significant change in stress scores is a pattern also shared by Tonge *et al.* (2006). Differences at baseline partially account for the lack of significant outcome in stress in this study (the home based group scores increased from a low stress level while the centre based group scores decreased from high stress). In addition to parent variables, Roberts *et al.* (2011) also separated and analysed the data for children with a diagnosis of ASD and found that, although there were no changes in terms of significant outcomes, these children appeared to show more improvements in social and communications skills in the centre-based intervention as opposed to the home-based intervention. Although not all of the child and parental comparisons produced significant results, the authors of this study concluded that centre-based treatments should be the preferred option over home-based interventions, except where contraindicated by family circumstances.

The findings from the included studies are not conducive to drawing conclusions about optimum intervention frequency and intensity. Two studies did not report a clear time frame for intervention (Bristol *et al.* 1993; Roberts *et al.* 2006), while four did not report clear information on the hours of direct contact with group or therapist through the intervention (Bristol *et al.* 1993; Greaves 1997; Pelchat *et al.* 1999; Roberts *et al.* 2006). Of the studies that did provide this information, it can be seen that there was wide variation in intervention frequency and intensity. The overall quantity of intervention ranged from zero hours for self directed intervention (Hudson *et al.* 2003) to 80 hours for an individualised parent programme (Roberts *et al.* 2011), with a mean of 26 hours. The mean length of

intervention was found to be 13 weeks. No patterns in outcome related to frequency and length of intervention could be seen. Some studies produced non-significant results after a 40 week programme (Roberts *et al.* 2011) while others reported significant reductions in parental mental health problems after six weeks (Keen *et al.* 2010). As this is a relatively under-researched area, there are no guidelines on the optimum intensity and time frame of intervention.

Of the seven studies that used a longitudinal follow-up design, mixed results were found. Kirkham (1993) found significant reduction in depression at post test and at follow up in their CBT group but not the parent support group. There was no difference in stress scores between the intervention groups at post test or follow up. Tonge *et al.* (2006) found positive mental health outcomes for parents attending two types of group intervention that were maintained at follow up. Roberts *et al.* (2006) compared an individualised intervention to a no-treatment control, for parents of children with LD/ ASD. Despite the large sample, this study found no significant effect of intervention on stress at post test or six month follow up. There seemed to be considerable variation in the interventions offered in this study, which reduces the reliability of these results, however a trend seems to be that improvements seen at post intervention are maintained in the longer term.

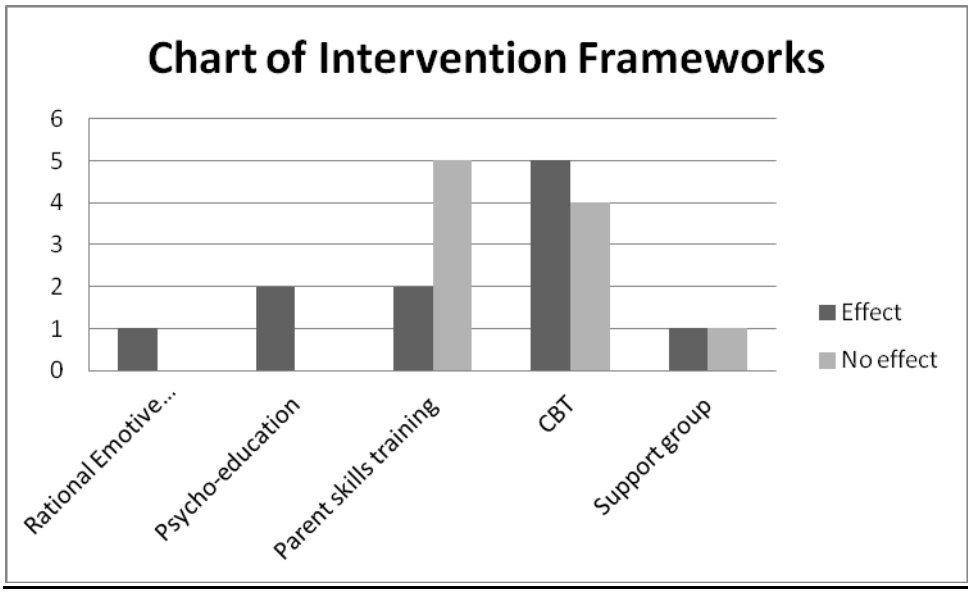
It is with caution that we draw any conclusions from the findings of the studies included in this review, however a general theme seems to be that short term interventions providing group and individual input based on parent skills training have most favourable outcomes for parents of children with LD/ ASD. The evidence

from the studies reviewed suggests that this is due to a combination of therapeutic input, and supportive contact with families and therapists. Given the trend for group based evidence based parenting interventions in the wider literature e.g. 'The Incredible Years' series (www.incredibleyears.com) and 'Mellow Parenting' (www.mellowparenting.org), it may be that this theme is due to more group based parent interventions being designed for this population of parents, and subsequently evaluated and published.

4.3. What is the evidence for the efficacy of interventions based on different theoretical frameworks?

Most of the studies selected for inclusion in this review contained elements of parent training and behaviour management (Chadwick *et al.* 2001; Gammon & Rose 1991; Hudson *et al.* 2003; Keen *et al.* 2010; Roberts *et al.* 2006; Solomon *et al.* 2008) while others focused on psycho-education (Bristol *et al.* 1993; Greaves 1997; Pelchat *et al.* 1999) or managing stress (Hu *et al.* 2010; Shu & Lung 2005). The remaining interventions incorporated more than one of these focus areas (Erguner-Tekinalp & Akkok 2004; Jocelyn *et al.* 1998; Kirkham 1993; Nixon & Singer 1993; Perry & Condillac 2010; Roberts *et al.* 2011; Schultz *et al.* 1992; Tonge *et al.* 2006). Although CBT and rational-emotive therapy have featured in this review, there is a lack of robust psychological frameworks within the sample of interventions. The proportions of different intervention models represented in this review are illustrated in figure 3.

Figure 3. Chart of intervention framework



We have seen that the most highly rated interventions in terms of quality provide some evidence to support CBT interventions, however parent skills training, including behaviour management also rated highly alongside these interventions (Keen *et al.* 2010; Kirkham 1993; Tonge *et al.* 2006). While Roberts *et al.* (2011) did not find evidence to suggest that parent skills training reduces mental health problems in centre or home-based interventions, the outcomes did reveal significant improvement in quality of life scores for the centre-based group over home-based and control groups. Although not explicitly presented as applied behaviour analysis, it seems that a behavioural theoretical framework may be providing a foundation for the more successful interventions, and subsequently impacting on parent mental health. This suggests that increasing parental skills in behaviour management is an indirect yet effective method of improving mental health. We know from the literature that interventions encompassing parent

training are likely to be effective in improving parental mental health, as a child's behavioural difficulties have been found to be reliably related to parental wellbeing (Hastings 2002), therefore the findings from this review have a footing in theoretical research.

The evidence from psycho-educational interventions is methodologically limited, but encouraging. Greaves (1997) found a rational emotive parent education (REPE) programme to be significantly more effective than an applied behaviour analysis (ABA) programme and a no-treatment control in reducing stress and low mood scores. While this finding appears to contradict the notion that behaviour management is most useful in improving mental health in parents, it should be noted that the quality of this study is weakened by sampling issues, lack of power calculation and inclusion of non-standardised outcome measures. Using a psycho-educational approach, Bristol *et al.* (1993) reported on long term improvements in depression for parents after an early psycho-educational intervention around the time of ASD assessment and diagnosis. Although the ability to generalise these results is limited due to methodological constraints, these findings suggest that providing education to parents in relation to understanding their child's difficulties and coping with their own stress are helpful to this population. Keen *et al.* (2010) also produced positive results in terms of parent stress and self efficacy in their professionally-directed psycho-education intervention.

Past research in this field has focused on CBT based groups for parents (Hastings & Beck 2004), although more recent meta-analyses have also considered alternative

models, such as parent training (Singer *et al.* 2007). The current review tells us that many of the interventions to support parents of children with LD/ASD are largely composed of parent training, psycho-education or behaviour management strategies. While the evidence base for these interventions seems to be promising, some authors have raised concerns that the scope of these interventions is too simplistic. In their study of psychological acceptance and its impact on psychological adjustment in fathers, MacDonald *et al.* (2010) highlight the role of multiple stressors, such as poverty and social exclusion (Emerson *et al.* 2006) and suggest that some parents may already have the appropriate parent skills, but are struggling to utilise them effectively under the load of multiple life stressors (MacDonald *et al.* 2010). This assertion provides theoretical support for the efficacy of parent support groups for multiply-stressed parents.

The outcomes related to non-specific parent support groups are somewhat limited from this review. Although the results from Tonge *et al.* (2006) appear to show that non-directive interventions have similar success rates to more standardised interventions, Shu and Lung (2005) found no difference in outcome between a non-directive support group for parents of children with ASD and a no-treatment control. It is noteworthy that the study by Tonge e*t al.* (2006) was rated highly in the quality criteria, whereas Shu and Lung (2005) were comparatively low in the quality rating. Studies in the field of parent adjustment have found that social support may mediate the impact of stress on parents of a child with LD/ ASD (Skok *et al.* 2006), suggesting that social support may help to enhance other types of intervention. The finding that higher quality studies demonstrate positive results for

non-specific parent support groups is promising; however the lack of research in relation to this type of intervention limits the scope for further critical analysis in this review.

5. DISCUSSION

5.1 Strengths and limitations of included studies and results

One of the positive factors to emerge from this review is the range of interventions that have been designed and evaluated, in the interests of serving the parents of children with LD/ ASD. Previous reviews of group interventions for this population of parents have highlighted the need for alternative interventions for families who do not respond to standardised packages (Hastings & Beck 2004). While the development of a range of intervention types is ultimately helpful in widening accessibility, the heterogeneity of the field makes it difficult to systematically analyse the outcomes. This means that, although a variety of interventions have been designed, we are not in a position to make confident recommendations about what type of model, intensity and delivery is most effective for whom. This is a drawback, both for the research field, and for service provision, in which a robust evidence base is increasingly required prior to investment. In this sense, the diversity of the field could result in decreased interest in implementing parent interventions at a service level.

At this time, firm conclusions cannot be drawn about the overall efficacy of parenting interventions from the evidence in the literature. Despite this, the findings from this review reveal that some interventions to support parents of

children with LD/ ASD may have a positive impact on parental mental health. The presence of a number of RCT and concurrent control studies suggests that the evidence base for these interventions is gradually strengthening, and the inclusion of gender as a variable of interest indicates that the field is becoming more inclusive. Despite this, the apparent outcome differences in sub-groups within parents (e.g. gender and marital status) cannot be fully explored due to a lack of high quality studies. Similarly, the evidence base for interventions based on child's condition is not equitable. Of the 20 studies included in this review, nine focused on parents of children with ASD. The other studies focused on parents of children with LD, although four of these detailed the inclusion of children with ASD within their LD criteria (Hudson *et al.* 2003; Kirkham *et al.* 1993; Nixon & Singer 1993; Schultz *et al.* 1992). This represents a fairly even split in terms of LD/ASD representation. Despite this, three of the four studies that rated most highly on the quality criteria included parents of children with ASD only. This means that, although LD and ASD were represented across the studies, the highest quality findings relate to parents of children with ASD only, which has implications in terms of a weaker evidence base for interventions for LD only.

The conclusions are hindered by methodological issues, preventing confident generalisation, however the findings provide support for the efficacy of different types of intervention delivery, intensity and theoretical frameworks. Specifically, the evidence seems to suggest that short term interventions, incorporating both group and individual support produce positive outcomes. While variety exists in terms of theoretical underpinnings for these interventions, CBT and parent skills

training (based on behavioural principles) appear to show particular promise. Group-delivered interventions were well represented within the sample, and it seems that these interventions contribute a socially-supportive element for parents. There was a trend towards higher rated studies including elements of individually administered support, which seemed to assist parents in applying skills. Although some studies found no difference in mental health outcomes between different modes of intervention delivery (Hudson *et al.* 2003), the majority of the evidence from higher quality studies seems to suggest that face-to-face peer and therapist contact is beneficial. The studies that were considered to be of comparatively higher quality in this review demonstrated efficacy of a combined parent training and support group (Roberts *et al.* 2011), cognitive behavioural groups (Kirkham 1993) and parent education and behaviour management groups (Tonge *et al.* 2006).

5.2 Findings in the context of wider research

The finding that CBT and parent skills training are showing promising outcomes for parental mental health is broadly consistent with meta-analyses and reviews undertaken in this area (Diggle & McConachie 2002; Hastings & Beck 2004; Singer *et al.* 2007). Inclusion criteria for this review differed from the previously published reviews. For instance, Hastings and Beck (2004) included only group based interventions, while Singer *et al.* (2007) included interventions in which the children, as opposed to parents, were participants. Despite the differences in inclusion criteria, the similar research conclusions in this review lend support to the validity of our findings. It is possible that multi-component interventions aimed at

improving a child's skills and behaviour will impact on parental stress differently from interventions aimed at developing parental skills. The former places more emphasis on child behaviour change and less emphasis on parenting change, which may result in less pressure on parents e.g. intervention attendance, time pressure, homework and performance pressure. Some authors have supported the notion that parent interventions can increase stress as a result of this increased pressure (Shu & Lung 2005), however the findings from this review and the evidence base overall appears to be weighted against this hypothesis. In their meta-analysis of stress management interventions, Singer *et al.* (2007) concluded that there was no evidence to suggest parent education and coping skills programmes increase parental stress, as all but one of the intervention studies they looked at showed reductions in stress. Findings in reviews by Hastings and Beck (2004), Diggle and McConachie (2002) and Barlow *et al.* (2003) also support the overall efficacy of parent interventions.

In recent years, acceptance and mindfulness-based approaches have gained increasing research focus as a support to parents of children with LD/ ASD. In their longitudinal study, MacDonald and Hastings (2008) found acceptance in mothers of children with LD had a bidirectional relationship with anxiety and depression. In a related study, MacDonald *et al.* (2010) found that fathers of children with LD who score highly on measures of acceptance and mindfulness tend to be more involved in parenting tasks, and report more positive gains associated with having a child with LD. The authors also found that acceptance partially mediates the impact of challenging behaviour on father's stress, anxiety and depression levels (MacDonald

et al. 2010). These findings indicate that acceptance and mindfulness based interventions may be of benefit to these parents.

Acceptance-based approaches e.g. Acceptance and Commitment Therapy (ACT) focus on a recognition and acceptance of unpleasant emotions, defusion (or stepping back) from negative thoughts and beliefs, and a process of clarifying values while empowering a client to move towards values related goals (Blackledge & Hayes 2006). Mindfulness approaches are underpinned by a non-judgemental focus on the present moment, allowing a person to consider alternative understandings and interpretations of a given situation (Kabat-Zinn 1994). Acceptance and mindfulness-based approaches have attractive face validity for use with this population of parents, as the negative thoughts and appraisals of these parents are not necessarily distorted or exaggerated. Indeed, Singer (1993) noted that some parents feel invalidated by interventions aimed at cognitive and emotional change (p.213). Additionally, acceptance and mindfulness-based principles may provide an effective framework for work with parents of children with LD/ ASD due to the long-term nature of the conditions.

Acceptance-based interventions have a good grounding in research for a number of conditions and disorders, such as anxiety disorders (Dalrymple & Herbert 2007; Soo *et al.* 2011; Twohig *et al.* 2006), depression (Forman *et al.* 2007), psychosis (Gaudiano *et al.* 2006; White *et al.* 2011), chronic pain (Wicksell *et al.* 2008) and trichotillomania (Woods *et al.* 2006). A small amount of published research exists on ACT-based interventions for parents of children with LD/ ASD (Blackledge &

Hayes 2006; Singh *et al.* 2006), and the overall trend is for positive parental outcomes in measures of mental health. The findings from these studies also demonstrate the mediational effect of enhancing satisfaction in parent-child interactions, and reducing problem behaviours in children on measures of parental mental health.

Blackledge and Hayes (2006) evaluated a two-day acceptance and commitment training workshop for parents of children with ASD, which aimed to address depression and distress through ACT processes such as identifying personally held values, and using creative hopelessness strategies to help parents access their longstanding emotional and cognitive methods of exercising control. Defusion exercises and metaphors also allowed parents to take a more objective stand point in relation to their 'unworkable' emotions. Active involvement in making commitments to accept difficult thoughts and emotions in the face of discomfort were also included. The results showed promise, with parents showing significant reduction in depression scores, experiential avoidance, cognitive fusion and automatic negative thoughts at follow-up. This study holds significant promise for ACT interventions, although the lack of control group meant that it did not meet inclusion criteria for this review.

The study by Singh *et al.* (2006) was also excluded from this review due to a lack of control group. In this study, the authors piloted an adapted mindfulness intervention with parents of children with ASD, an approach which had already been found to have positive outcomes with staff working with people with multiple

disabilities (Singh e*t al.* 2004). This mindful parenting approach also shares common elements with mindfulness processes that have been applied within the parenting literature for neuro-typical children (see Duncan *et al.* 2009, for an overview). Using three mother-child dyads, Singh *et al.* (2006) found that a 12 week mindfulness training programme, focusing on parental self-management resulted in large and sustained reductions in problematic child behaviours in the following 52 week 'mindfulness practice phase'. Parents' ratings of satisfaction in interactions and parenting also increased over the same time period. The authors acknowledge that further research will be necessary to define the processes underpinning the improvements made with mindfulness interventions, although they speculate that mindfulness allows parents to disengage with intergenerational parenting styles and consider alternative interpretations and possibilities in relation to their parenting role.

These preliminary findings suggest that acceptance and mindfulness based interventions can be of benefit in supporting parents of children with LD/ ASD, perhaps where other evidence based interventions have been less effective. Singh *et al.* (2006) noted that the most significant changes in mother's parenting styles occurred in the 52 weeks following training, therefore longitudinal and follow-up research may be most effective in highlighting the potential gains from ACT and mindfulness-based parenting interventions for this population.

5.3 Recommendations for future research

We have seen that the evidence base for interventions aimed at improving the mental health of parents with children who have LD/ASD is developing. In order for this research field to become robust, a number of recommendations can be drawn, based on this systematic review of the literature. The higher quality evidence in this field is largely weighted towards parents of children with ASD. Expanding the field to include more high quality studies with parents of children with other disorders will be of benefit, as there is little evidence in the literature to suggest that parents of children with ASD are more at risk of maladjustment than parents of children with other intellectual disabilities, and thereby more in need of tailored interventions.

As discussed earlier, the need for further standardised models of parent intervention will serve to increase the evidence base for different types of intervention, and also allow for comment on optimum intervention intensity, duration etc.

The included studies showed a tendency for recruiting participants through non-clinical settings. While this increases the potential for generalising findings to a larger population, we note that there were instances in which baseline scores on mental health symptoms were within the non-clinical range (e.g. Roberts *et al.* 2006; Tonge e*t al.* 2006). It may be that this impacted negatively on the findings of these studies, as the potential for significant improvement following intervention was minimal, and the risk of type II errors is subsequently increased. Recruiting

based on parental mental health as opposed to child's diagnosis may result in a more valid sample from which to generalise results to parents with mental health problems that fall within the clinical range. Conversely, the finding that mental health outcome measures may not be capturing intervention effects for parents out with the clinical range provides support for the use of outcomes that measure non-clinical concepts, such as parental self efficacy and locus of control. Non-clinical outcome measures allow us to quantify intervention effects in parents with no pre-existing mental health difficulties, in addition to allowing for comment on meditational effects of constructs such as confidence, satisfaction and control on parent adjustment.

Future evaluation will benefit from increased use of standardised measures, improving the reliability of comparison between studies. This review has also highlighted a need to include objective outcome measures as a method of reducing bias through self-report measures. For example, Roberts *et al.* (2011) included pre and post self-report and clinical observations of parental positive behaviour change, and found that parents reported making behaviour changes which were not observed at clinical observation. This highlights the disadvantage of using self-report measures with no objective method of verification. Roberts *et al.* (2011) reported administering the parental mental health outcome measures through semi-structured interview, while Erguner-Tekinalp & Akkok (2004) included an additional qualitative interview to support the standardised outcomes. In this study, parents reported a post-intervention reduction in stress when interviewed, but this was not reflected in post intervention scores on the outcome measures. These

examples suggest that adding a post-intervention semi-structured or qualitative interview may go some way to addressing the issue of reliability in the self-reported outcome data.

The results from studies that included a longitudinal element were mixed, however the studies that reported follow up measures suggest promising longitudinal effects of intervention. Bristol *et al.* (1993) found significant reductions in depressive symptoms in the treatment group at 18 months post intervention, an effect that was not present at six months post intervention. This delayed treatment effect was also found in Kirkham (1993), in that the treatment group demonstrated significant reduction in depression at two year follow up, which was not significant at post-intervention. These findings suggest that relatively short term interventions can have increasingly beneficial effects on depression after treatment. However, the findings also highlight the need for methodological development, to reduce the risk of type II errors. Further longitudinal research in this field will also add to the research quality, and allow for more robust predictions of outcome. For example, following up participants to at least six months post intervention – preferably 18 months – would be advantageous in future studies, to allow for monitoring of delayed intervention effects.

A strength of this study is the focus on early intervention for families. Many of the interventions reviewed were implemented within the pre-school period, or around the time of early diagnosis (Bristol *et al.* 1993; Greaves 1997; Keen *et al.* 2010; Pelchat *et al.* 1999; Perry & Condillac 2010; Roberts e*t al.* 2006; Roberts *et al. 2*011;

Tonge *et al.* 2006). This fits with the notion of positive prevention, providing support to families before patterns of challenging behaviour and maladjustment become entrenched (Hudson *et al.* 2003). Although some evidence exists to suggest positive longitudinal effect of early intervention, we must be cautious in our assumptions. The understanding of family adjustment trajectory in this population is not well researched, and as such, the potential for parent intervention at later points in the child's life span must be held in mind. Further research into interventions for parents of older children may shed some light on the mental health needs of this population of parents over time.

While the evidence base is increasing, research findings are becoming incorporated into Governmental recommendations. For example, the Psychological Therapies Matrix (The Scottish Government 2011) recommends the use of parent education for parents of children with ASD, regardless of ASD severity. Despite this, work remains to be done in determining the efficacy and applicability of parent interventions. We have begun to see a move towards recognising and accounting for multiple factors in the consideration of intervention effectiveness e.g. culture, gender, family context. As future research continues the consideration of these factors, we may see alternative theoretical frameworks developing a firmer footing in the literature. This may lead to increased availability of appropriately diverse, empirically supported provision for parents of children with LD/ ASD.

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PART 2. RESEARCH PAPER

An investigation into the factors that impact on adjustment in parents of children with a learning disability and/ or autism spectrum disorder

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1. ABSTRACT

Background Previous research has shown that parents of children with learning disabilities (LD) and/ or autism spectrum disorders (ASD) are more psychologically distressed than parents of neuro-typical children. The literature suggests that there is significant variation in the rates of maladjustment within this population, and the research into factors that influence parental adjustment is developing. This study aims to add to the research into the factors influencing adjustment to parenting a child with LD/ ASD. In particular, relatively under-researched concepts such as parental acceptance, time since diagnosis, and the influence of informational support to understand a child's needs, will be explored.

Method Two hundred and sixteen parents of children aged 4-19 participated in a questionnaire study, conducted through local additional support needs (ASN) schools and bases. Measures of psychological adjustment were gathered alongside measures of acceptance, positive gains, level of child's challenging behaviour and demographic information.

Results Along with other variables, psychological acceptance and was found to account for significant variance in parental adjustment. There were no observed relationships between adjustment and time since diagnosis, or level of informational support.

Conclusions The results have implications for the understanding of the role of acceptance in parent adjustment. Implications for intervention development and

future research directions are discussed, in addition to the methodological limits of the study.

Keywords Learning disability, autism spectrum disorders, parent adjustment, acceptance, informational support

2. BRIDGING CHAPTER

While the preceding systematic review of the literature focused on interventions to support parents of children with LD/ ASD, the focus of this research project is to explore the factors that influence parental psychological adjustment to a parenting a child with LD/ ASD. As discussed in the preceding review, there is significant variation in the reported distress levels of families who care for a child with LD/ ASD, and the factors that influence this are not fully understood. The literature is not clear as to the wider psychological processes that determine healthy adjustment in this population of parents, although the definitions – and processes being studied – are developing. This chapter will briefly review the factors that have been found to account for some of the variance in parental adjustment, and will provide a rationale for further exploration of factors from the wider disability research, which may be pertinent to this population.

2.1. Background to adjustment in the literature

Adjustment has been defined as 'coming to terms with pain or limitations…and an attempt to resolve the dual demands of symptoms and society (p.156)' (Radley, 1994). This definition suggests that it is not only factors associated with illness or disability that influence adjustment, but also the social context within which these symptoms occur. Historically, parental adjustment to a child's LD/ ASD has been conceptualised using a number of constructs, including mental health (Lloyd & Hastings, 2008; Glidden & Schoolcraft, 2003), stress (Hill & Rose, 2009), coping style (Trute *et al.,* 2010), parenting satisfaction (Dukmak, 2009) and parental locus of

control (Lloyd & Hastings, 2009a). A large proportion of the research into parental adjustment has focused on the presence of depressive and anxiety symptoms in addition to stress (Lloyd & Hastings, 2008, 2009a, 2009b; MacDonald *et al.,* 2010).

Although a large part of the research in psychological adjustment has been conducted with mothers (e.g. Hassal *et al*., 2005; Lloyd & Hastings, 2008), there has been relatively recent interest in the adjustment of fathers to a child's LD/ ASD (e.g. MacDonald *et al.,* 2010). Research suggests that mothers report more adjustment problems than fathers (Heller *et al*., 1997), and that paternal and maternal adjustment are predicted by different variables (Saloviita *et al*., 2003). This represents challenges for researchers in terms of generalisation, and also service providers in terms of supporting both parents.

We can see that the field of research into factors associated with parent adjustment to a child's LD/ ASD is broad and varied, but can be roughly distinguished into three areas - child characteristics, parent characteristics and contextual family factors. While we acknowledge the impact of factors such as poverty and parental resources on levels of distress (Emerson *et al.,* 2006) these parental and family factors are not necessarily amenable to change at a therapeutic level. As such, the current study will focus on the psychological factors and processes involved in adjustment.

2.2. Child characteristics and adjustment

In looking at child characteristics, some studies have found associations between severity of LD/ ASD and parental stress (Minnes, 1988) and level of communicative skill and parental stress (Frey *et al.,* 1989). Despite this, further research has

indicated that level of challenging behaviour is a better predictor of parenting stress and burden than type or severity of disorder (Baker *et al.,* 2003; Quine & Pahl, 1991). The processes through which challenging behaviour can be understood and addressed are well established and have strong research backing (e.g. functional analysis, applied behaviour analysis), therefore the current study will focus on some factors related to parental adjustment that have relatively less research backing - parental cognitive factors (such as acceptance), contextual factors relating to support to understand the child's needs, and the impact of time and age of the child in parental adjustment. While this chapter categorises factors related to adjustment based on simple definitions, we are keen to highlight that this serves the purposes of summarising the research, and is not an attempt to undermine the complex relationships that exist between the factors relating to adjustment.

2.3. Adjustment and parental cognitions

Within the past 20 years, parental cognitive factors have begun to be increasingly analysed in relation to adjustment, within the LD/ ASD literature. Research into parental locus of control (Lloyd & Hastings, 2009a), parental self-efficacy (Hastings & Brown, 2002) and parental acceptance (Lloyd & Hastings, 2008) appear to demonstrate that parental cognitions are associated with well-being and adjustment, both cross-sectionally and longitudinally (Lloyd & Hastings, 2009a). These findings are important and promising, as cognitive factors are amenable to psychological intervention, suggesting that therapeutic routes may be of benefit to this population.

2.3.1. Adjustment and acceptance

Psychological acceptance is a concept that has recently attracted interest within the field of disability research. Previously, acceptance was largely studied within the fields of physical health and mental health. McCracken and Ecclestone (2003) found that acceptance of chronic pain was associated with reduced depression, pain-related anxiety, and disability, and accounted for more of the variance in pain adjustment than coping strategies. In a study investigating acceptance of disability in a sample of paraplegic participants, those with high levels of acceptance reported higher self-esteem and quality of life than those with low or moderate levels of acceptance (Ferrin *et al.,* 2011). Moving into the acceptance of LD/ ASD field, Lloyd and Hastings (2008) found that mothers who were generally more accepting reported fewer psychological adjustment problems, in relation to raising a child with LD/ ASD. The same study demonstrated that acceptance is bi-directionally associated with maternal anxiety and depression, through longitudinal analysis. Taken together, results from research into parental acceptance appear to indicate that acceptance may be a construct of parental adjustment overall, although further research is needed to consolidate this finding. MacDonald *et al.* (2010) found that acceptance in fathers of children with LD/ ASD partially mediates the impact of behaviour problems upon paternal stress, anxiety and depression. This study used an adapted version of the Acceptance and Action Questionnaire II (AAQ-II: Bond *et al.,* 2011), in order to measure parental acceptance to a child's LD/ ASD specifically. Although not longitudinal, the results of this study add support to the existing literature in the area of acceptance of disability, by measuring levels of

acceptance in relation to a specific life stressor. This allows for more specific investigation of parental acceptance of a child's LD/ ASD, which may differ from a parent's rating of general acceptance that has previously been used in the adjustment literature.

2.3.2. Adjustment and positive gains

The other construct that the current study will explore is the notion of positive family gains associated with raising a child with LD/ ASD. While we have acknowledged the increased stress associated with raising a child with LD/ ASD, research has suggested that families will not necessarily experience high levels of pathology and, that some families recognise the positive experiences associated with this (Flaherty & Glidden, 2000; Hastings, Beck *et al.,* 2005; Trute *et al.,* 2010). The capacity of families of a child with LD/ ASD to report both positive and negative experiences in relation to their role has been noted (Hastings & Taunt, 2002; Hastings, Beck *et al.,* 2005), and this has been conceptualised theoretically using the two-factor model of care giving (Lawton *et al.,* 1991). This model proposes that the positive and negative characteristics of the cared-for person provide two independent pathways to care giving outcomes. According to the model, difficult characteristics, such as challenging behaviour, impact upon perceived level of burden for the care-giver, which then lead on to negative care-giver outcomes such as stress and anxiety. In addition, positive characteristics of the cared-for person, such as a good relationship with the care-giver, can lead to positive appraisals in the care-giver, affecting positive care-giver outcomes, such as satisfaction with role.

This model highlights the potentially important role of perceptions of positive gains in the care-giver, while also acknowledging the presence and impact of negative perceptions.

A number of studies have investigated the concept of co-existing positive and negative experiences of raising a child with LD/ ASD (Altiere & von Clunge, 2009; Flaherty & Glidden, 2000; Green, 2007; Hastings & Taunt, 2002; Trute e*t al.,* 2007), however the associations with adjustment outcomes have shown some variability (Lloyd & Hastings, 2008; MacDonald *et al.,* 2010). The role of positive perceptions in parental adjustment is likely to benefit from further investigation.

2.4. Adjustment and informational support

In addition to the child's disability characteristics, and parental cognitive factors that have been discussed, a number of additional family and contextual factors have been found to be related to parental adjustment to a child's LD/ ASD. Many of these, including availability of social and spousal support (Bristol *et al.,* 1988), family income (Singhi *et al.,* 1990; Farmer *et al.,* 2004) have been relatively well researched. Drawing on the wider disability adjustment literature, there are a number of factors that do not appear to have been researched in populations of parents with a child with LD/ ASD. While social supports and professional supports such as respite have been found to impact on parent wellbeing (Skok *et al.,* 2006), there has been relatively little research into the impact of informational support from services, e.g. the impact of disorder specific information on parental adjustment (Bailey & Simeonsson, 1988), and signposting to relevant informational

support services (Farmer *et al.,* 2004). In addition to professionally guided and supported information provision, understanding can also be enhanced through self-help resources e.g. accessing information through websites and charitable organisations such as the National Autistic Society or Mencap. The relationship between increased understanding of a child's needs and parent adjustment is not well understood, and further research is needed.

2.5. Adjustment over time

Another area of interest within the chronic illness and disability literature is the passage of time and adjustment. Some research in the field of adjustment to physical and chronic illness has shown adjustment to be positively correlated with time since onset (e.g. Kovacs *et al.,* 1986). This supports the notion of an initial process of grief, followed by gradual adaptation with the passage of time, and suggests that time alone is a 'great healer'. This has attractive face validity, and has theoretical underpinnings in the models of grief and loss e.g. Kubler-Ross' stages of grief model (1969). There is some controversy within the literature about improvements in adjustment over time, for example, Pless *et al.* (1972) speculated that their finding of increased psychosocial disturbance in adolescents with chronic illness as opposed to younger children, may be attributable to cumulative effects of poor health over time. Johnson and Meltzer (2002) also suggest that the process of adjustment may not be linear, and that the role of developmental characteristics of chronic conditions must be acknowledged in this process, in addition to child physical and cognitive development. In their paper on health and quality of life, Carr

et al. (2001) contend that perceptions and meanings attached to 'health' vary over time, and that a central dichotomy in this adjustment process is the balance or imbalance between expectations and experience. As an alternative to the time-bound grief theory of adjustment, Olshansky (1962) put forward a hypothesis that parent's adjustment to their child's LD/ ASD may be characterised by periodic sadness throughout the developmental lifespan. Although the term 'chronic sorrow' was used to describe this process, the author characterised this as normal grief, and understood that these parents experienced 'peaks and troughs' at specific developmental milestones, rather than a continual pattern of sadness.

2.6. Models of parental adjustment to a child's LD/ ASD

McCubbin and Patterson (1983) developed a multivariate 'double ABCX' model in order to conceptualise variables in family adaptation. This model built on the ABCX model (Hill, 1949, 1958), which focused on pre-existing family resources in predicting response to 'crises' or stressors. This 'single' ABCX model was expanded by McCubbin and Patterson's to include post-stressor variables, which conceptualise the role of secondary stressors and also coping resources learned in response to the 'crisis'. The pre and post 'crisis' models effectively create a double ABCX model, in that they propose a two-factor model of adjustment. Post-stressor variables include pile-up of demands, such as chronic strains, financial implications and ambiguity associated with the stressor (aA), the development of new resources to manage e.g. responsibilities, increased self-confidence and educational, support and social need (bB) and changed perceptions of the original stressor (cC) (Weber,

2011; Pakenham *et al.,* 2005). Post crisis adaptation serves as an outcome variable (xX). These additional variables are thought to reflect the fluid and evolving nature of stressor impact and appraisal within a family.

The double ABCX model has been adopted within the disability research to conceptualise family adjustment and coping. Bristol (1987) demonstrated that the factors associated with adjustment e.g. severity of disability (aA), level of support (bB) were effectively conceptualised by individual elements of the model, and showed that these were predictive of maternal adaptation to parenting children with disabilities (xX) using multiple regression analysis. Similar findings were produced by Saloviita *et al.* (2003). This study also found that negative coping strategies, such as self-blame, wishful thinking and avoidance (bB) were significant predictors of parent stress (xX). Pakenham *et al.* (2005) and Jones and Passey (2004) have also demonstrated effective application of the double ABCX model to families of children with developmental disabilities

A recent and related model is the multidimensional model of parent coping (Kaniel & Siman-Tov, 2011). Although new to the research field, this model brings together a number of existing frameworks, such as the transactional model of stress and coping (Lazarus, 2001; Lazarus & Folkman, 1984) and the double ABCX model (McCubbin & Patterson, 1983). This model combines parental psychological resources, stress appraisal and adjustment to conceptualise coping in mothers and fathers. The model conceptualises adjustment as 'reaching a balance between the demands of the stressors and the psychological resources' (Lazarus & Folkman,

1984), and defines this using parental mental health outcomes and quality of marriage. Using path analysis, the authors claim that the model is an appropriate framework from which to conceptualise parental coping. Future research including single parent families will be required in order to comment on the wider application of the model.

In order to root the proposed models within empirical research, it will be necessary to follow families through the process of adjusting to their new found roles. Further within-subjects, longitudinal research will allow for model development.

A possible limitation of these models is that they do not effectively demonstrate the process of adjustment over time. Although the published research in this area is limited, and therefore restricts model development, the hypothesis put forward by Calman (1984) may be useful in conceptualising adjustment over time. Calman (1984) proposed a conceptual framework for variations in quality of life for people diagnosed with cancer, and underpins the proposition put forward by Carr *et al.* (2001) that quality of life over time can be conceptualised as interplay between expectations and experience at various time points. Calman's hypothesis seems applicable to parents of children with LD/ ASD, who may experience multiple adjustment processes as pre-existing expectations based on neuro-typical frameworks of infant, child and adolescent life stages become asynchronous with their experiences. This allows us to conceptualise the importance of informational supports to aid parents in understanding their child's needs, in terms of aligning expectations and experiences. It is tempting to elaborate on the expectation

alignment theory and speculate that expectations and experiences can be aligned at one stage e.g. parenting an infant with LD/ ASD, but may become asynchronous at future stages e.g. parenting an adolescent with LD/ ASD. This may explain the apparent lack of evidence for the linear or stage model of adjustment in this population. It is important to note that this hypothesis has not been expanded into a model, nor has it been applied out with quality of life research, however, in the absence of developed models, it has attractive face validity as a potential framework for understanding adjustment over time in this population of parents. Research in the field of longitudinal adjustment in parents is sparse and the scope for comment on the adjustment models and processes for this population of parents is limited. The lack of research also has negative implications for measurement and intervention planning (Antonak & Liveh, 1992). Further investigation of longitudinal patterns of adjustment may be of interest in conceptualising adjustment over time.

This chapter has highlighted some of the factors known to be involved in parental adjustment to a child's LD/ ASD, in addition to some relatively under-researched factors from other research fields. The preceding systematic review has demonstrated that interventions to support parents of children with LD/ ASD can improve parental mental health, child functioning and parental overall wellbeing. Despite this promising evidence, continued research is required to clarify the different factors that influence parental adjustment, in order that interventions can be designed and implemented according to evidence-based frameworks. The current study will examine the extent to which time since diagnosis, parental

acceptance of their child's LD/ ASD and informational support in relation to their child's specific needs influence parental adjustment. In doing so, we hope to add to the existing literature on parental adjustment, consolidating an evidence base that will allow for continued development of parental interventions.

2.7. Hypotheses

1. Parental acceptance will account for significant variance in parental psychological adjustment, after controlling for demographic, child-related and parent-related variables known to influence outcomes

2. Time since diagnosis will account for a significant proportion of the variance in parental psychological adjustment

3 Informational support to understand their child's needs will account for a significant proportion of the variance in parental psychological adjustment

3. METHODOLOGY

3.1 Design

In this study, a within-subjects, single group design was used with a population of parents of children with LD/ ASD living within the community. The design is similar to that used by other studies examining the impact of demographic and cognitive factors on parental adjustment (Lloyd & Hastings, 2008; MacDonald *et al.,* 2010).

3.2 Participants

3.2.1 Identification of participants

Parents or key carers of children with LD/ ASD were recruited through primary and secondary additional support needs (ASN) schools, and from specialist ASN bases within mainstream schools. All schools and bases were located within North Lanarkshire Local Education Authority (LEA). Fifteen schools were approached and all agreed to participate.

3.2.2 Inclusion and exclusion criteria

All parents and carers, male and female were included in the distribution. While other studies looking at adjustment and acceptance have limited inclusion on the basis of gender (e.g. Lloyd & Hastings, 2008; MacDonald *et al.,* 2010), the

exploratory nature of the time and professional support factors being considered within this study led to the decision to open the inclusion criteria. There were no limitations on the age of the parent. To meet inclusion, each participant must be caring for a child diagnosed with LD or ASD, aged under 19 years, who attends a ASN school or base within North Lanarkshire LEA.

3.2.3 Power considerations

Formulae detailed in Green (1991) to evaluate sample size in multiple regression coefficients with a power of 0.80 - a value proposed by Cohen (1988), as an appropriate level for use in behavioural sciences research - were used to consider sample size in this study. Setting alpha at 0.5, the traditional level of probability, and taking into account the number of independent variables in this study, we calculated that a sample size, based on a conservative estimate of effect size (medium) should be between 117 and 138.

3.3 Measures

3.3.1. Dependent variables

Hospital Anxiety and Depression Scale (HADS: Zigmond & Snaith, 1983). Past research using the HADS with mothers of children with LD/ ASD has shown that the scale maintains good reliability (Cronbach's alpha coefficient in excess of 0.8)

(Hastings & Brown, 2002). The HADS has been used as a measure of parental psychological adjustment in much of the quantitative research in the field of disability e.g. Hastings and Brown (2002), Hastings (2003), Lloyd and Hastings (2009a, 2009b). The HADS has been used extensively in community populations despite original development for hospital populations (MacDonald *et al.,* 2010).

Parent and Family Problems sub-scale of the Questionnaire on Resources and Stress Friedrich short form (PFP of QRS) (Friedrich *et al.,* 1983). This is a measure of parenting stress. Previous research with parents of children with LD/ ASD used an amended version of this scale, removing five items that have been shown to constitute a robust measure of depression in parents of children with LD/ ASD (Glidden & Floyd, 1997). More recent research has found the scale to have a correlation coefficient of between 0.86 (Lloyd & Hastings, 2008) and 0.90 (MacDonald *et al.,* 2010) for a total score derived from the remaining items.

The Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS: Tennant *et al.,* 2007) is a 14-item measure relating to different aspects of positive mental wellbeing. It has good internal validity, and has been demonstrated to have a Cronbach's alpha of 0.91 in a population sample during development (Tennant *et al.,* 2007). The WEMWBS has been shown to have a significantly high correlation with other measures of affect and wellbeing e.g. Scales of Psychological Wellbeing (r=0.74, p<0.001), and the Positive and Negative Affect Scales (r=0.71, p<0.001) (Tennant *et al.,* 2007). This scale has also been used in populations of parents, and has

contributed toward the development of two post-natal health instruments (Morrell *et al.,* 2011)

The Satisfaction with Life Scale (SWLS: Diener *et al.,* 1985). This 5-item scale has been developed to provide a discrete measure of life satisfaction, and has been found to have good internal consistency (Cronbach's alpha of 0.87 found by the authors). Satisfaction with life is a concept that has been interpreted as a construct of psychological adjustment within disability research (e.g. Dahlbeck & Lightsey, 2008), however it does not appear to have been widely researched in relation to a parent's psychological adjustment.

3.3.2 Predictor variables

The Positive Gains Scale (PGS: Pit-Ten Cate, 2003) has been used as a measure of positive experiences associated with raising a child with LD/ ASD. The scale consists of five questions that assess perceived parental benefit of raising a child with LD/ ASD, and two questions relating to family gains. Preliminary research suggests that the scale has face and content validity, and has been assessed as having a Cronbach's alpha of 0.79 (Pit-ten Cate, 2003) and 0.80 (MacDonald *et al.,* 2010).

'AAQ-Intellectual Disability Parent' scale (AAQ-IDP: MacDonald *et al.,* 2010) is an adapted version of the Acceptance and Action Questionnaire-II (AAQ-II: Bond *et al.*, 2011). This adapted, eight item scale has been developed and used by MacDonald

et al. (2010), in their study of fathers' acceptance in a clinical sample. It was found to have a Cronbach's alpha coefficient of 0.80. This is a specific measure of acceptance in relation to parenting a child with LD/ ASD, as opposed to a general measure of acceptance, which has historically been used in this research field.

Strengths and Difficulties Questionnaire (SDQ: Goodman, 1997) is a brief, well-validated measure of clinically significant challenging behaviour in children. Previous research suggests that good levels of reliability are maintained when used with a population of parents of children with LD/ ASD, e.g. Cronbach's alpha coefficient of 0.88 (Lloyd & Hastings, 2009a).

3.3.3. Demographic and background information

A questionnaire designed by the lead researcher was included in each questionnaire pack to gather relevant demographic information, and details about the child's conditions or diagnoses. A copy of this questionnaire is included in appendix B.

3.4 Procedure

Questionnaire packs were distributed to parents of children attending ASN schools/ bases in North Lanarkshire LEA. Questionnaire packs were handed to Head Teachers, and sent home, addressed to parents, in the children's school bags. Two sets of questionnaires were included in each pack, to allow two parents, or a second

key carer to participate. All data collected by questionnaires was anonymous, and the questionnaires asked for no personally identifiable information. Consent to participate was implied through return of questionnaires. An information sheet advised parents of the likely time implications of participating, provided a rationale for the study, and explicitly stated that participation in the study was optional (see appendix A). The sheet also included a telephone number for the lead researcher, in order that parents could direct questions and comments to an appropriate person. This removed time pressure on school staff to aid with the completion of questionnaires. A self-sealing envelope was provided with the questionnaires to ensure that questionnaire responses were only seen by the lead researcher. Completed questionnaires were returned to school in sealed envelopes, to be collected by the lead researcher. Distribution and collection took place in March 2012.

Of the 15 schools and bases approached, all agreed to participate. A total of 1595 questionnaires were distributed to parents. Of these, 235 questionnaires were returned (a response rate of 14.7 per cent).

3.5 Ethical issues

Ethical approval for the project was granted by the University of Edinburgh, School of Health and Social Science Research and Ethics tutor in December 2011 (see appendix C). Approval to approach North Lanarkshire ASN Head Teachers to distribute questionnaires was granted by the North Lanarkshire LEA Education

Officer for Additional Support Needs at a meeting in February 2012. Individual meetings were arranged with Head Teachers to explain the purpose of the study, answer any questions, and invite the schools to participate.

4. RESULTS

4.1 Data analysis plan

Homogeneity of variance between schools and diagnostic groups was checked using Levene's test. Group differences in outcome were indicated, therefore the variables of 'school' and 'diagnostic group' were entered into the regression analysis to control for the effect these variable may have on the dependent variables. Preliminary analyses were carried out in order to investigate assumptions of linearity and normality in the overall sample. Spearman's correlation analyses were completed to examine the relationships between each of the interval level outcome and predictor variables, each tested at .05 level of significance. Mann-Whitney tests were carried out on all dichotomous predictors with the outcome variables at the .05 level of significance. Regression analyses were subsequently completed, examining all significant predictor variables against the outcome variables, controlling for variables of diagnostic group and school. Kruskal-Wallis tests were completed to investigate differences in parental adjustment between child age groups.

4.2 Preliminary analysis

4.2.1 Data integrity

All data was screened to identify missing data and incorrectly assigned codes. One parent failed to report their child's age, and 31 parents did not report their own age. These missing values were replaced with the series mean.

Of the parents that stated their child had a diagnosis (216), 27 did not provide a date upon which their child was diagnosed. Twenty-two carers failed to report their marital status, and 15 did not report the level of support that they had received from services. Eight failed to specify whether or not they had accessed self-help materials. The rate of non-responding for these items was problematic, in that the information did not lend itself to missing value analysis (MVA). These variables were included in subsequent analysis using listwise deletion. Although this reduced the sample size in analyses involving these variables, the smallest sample size resulting from the listwise deletion was 156. This is greater than the minimum sample size required to detect a medium effect, according to our power calculations, therefore listwise deletion was considered to be an appropriate method of dealing with the missing data for these variables. Missing values from the standardised questionnaires were replaced with the series mean.

4.2.2 Reliability

Reliability analyses were carried out for each of the measures used, and were found to be adequate to excellent. With the exception of the Strengths and Difficulties Questionnaire (SDQ), each measure achieved Cronbach's alpha coefficient of above 0.8 (see table 1.)

Table 1. Reliability of measures

Measure	Subscale	Cronbach's alpha
AAQ-IDP	Total	0.85
HADS	Total	0.90
	Anxiety	0.86
	Depression	0.84
PGS	Total	0.80
PFP subscale of QRS	PFP	0.88
SDQ	Total	0.71
SWLS	Total	0.89
WEMWBS	Total	0.94

4.2.3 Analysis of assumptions for variable: diagnostic groups

In order to examine homogeneity of variance between diagnostic groups, the distributions for each scale variable were assessed for normality within each of the diagnostic groups (children with LD only, children with ASD only, children with LD and ASD) using histograms, skew and kurtosis values, and z-scores. When examined within groups, all variables failed to meet assumptions of normality due to significant skew and kurtosis (values were significantly above or below zero). Each variable was transformed using square root and log in order to increase normality. Square root transformations were found to improve the normality of the distributions within diagnostic groups. Assumptions of normality between diagnostic groups were upheld as a result of all z-scores for skew and kurtosis falling within the non-significant range (p=<1.96), with the exception of the 'parents years in education' variable.

Sample sizes between diagnostic groups were found to be unequal (n= 92, 88, 36). Levene's test was applied to the transformed data and the results demonstrate that

the variances between groups were not significantly different. In addition, variance ratios were examined, and found to be adequate (the difference between the largest and smallest group variables was found to be less than the critical value for Hartley's F_{max} test). As a result of non-significant Levene's statistics and acceptable variance ratios, the assumption of homogeneity of variance between diagnostic groups was upheld.

Following transformation and examination, an analysis of variance (ANOVA) was carried out to investigate outcome variable differences between diagnostic groups. The results demonstrate a significant effect of diagnostic group on the following variables: time since diagnosis, strengths and difficulties score, positive gains score, satisfaction with life, stress score, parental wellbeing, and child age. This indicates that, within our sample, the parents of children falling into different diagnostic categories (LD only, ASD only, LD and ASD) differed on the parental adjustment outcome variables. Details of assumptions analysis and ANOVA for diagnostic groups can be found in appendices E and F.

4.2.4 Analysis of assumptions for variable: schools

In order to examine homogeneity of variance between school groups, the distributions for each scale variable were assessed for normality within each of the fifteen schools using histograms, skew and kurtosis values, and z-scores. When examined within groups, all variables failed to meet assumptions of normality due to significant skew and kurtosis (values were significantly above or below zero).

Square root transformations were found to improve the normality of the distributions within school groups. Within the groups, assumptions of normality were upheld as a result of all z-scores for skew and kurtosis falling within the non-significant range (all z-scores <1.96).

Sample sizes between groups were found to be unequal (*n*= 6 to 39). Levene's test was applied to the transformed data and the results demonstrated that the variances between groups were significantly different. In addition, variance ratios were examined, and found to show significant variation between the groups (the difference between the largest and smallest group variances was found to be greater than the critical value for Hartley's F_{max} test). As a result of significant Levene's statistics and unacceptable variance ratios, assumptions of homogeneity of variance between schools were not met.

Following transformation and examination, an analysis of variance (ANOVA) was carried out to investigate differences in outcome variables between schools. An alternative *F*-ratio (Welch's *F*) was interpreted for the four variables that demonstrated heterogeneity of variance, as this statistic has been found to be robust when the homogeneity of variance assumption has been violated. The results demonstrate a significant effect of school on the following variables: strengths and difficulties score, stress score, parental wellbeing and child age. This indicates that, within our sample, the parents of children attending different ASN schools, differed on the parental adjustment outcome variables. Details of

assumptions analysis and ANOVA for diagnostic groups can be found in appendices G and H.

4.2.5 Full sample distributions and data transformations

The distributions for each scale variable were assessed for normality. Distributions were examined using histograms, skew and kurtosis, z-scores and Kolmogorov-Smirnov statistics.

All variables, with the exception of parent age, SDQ score and wellbeing score failed to meet the assumptions of normality, due to significant skew/ kurtosis z-scores. Each variable was transformed using square root and natural log in order to increase normality, however examination of the resulting z-scores demonstrate that transformation was not successful in normalising the data. Results of data transformations can be seen in table 2.

Table 2. Data Transformations

Variable	Transformation	Skew (z-score)	Kurtosis (z-score)	Kolmogorov-Smirnov (*p*=)
Parent age	Non-transformed	-1.00	0.28	.061 (.200)
	Square root	-2.05	-0.56	.076 (.081)
	Natural log	-3.11	0.17	.008 (>.001)
Parent years in education	Non-transformed	9.77	7.79	.246 (>.001)
	Square root	8.60	5.55	.240 (>.001)
	Natural log	7.55	3.76	.245 (>.001)
Child age	Non-transformed	0.00	-3.36	.094 (.004)
	Square root	-1.37	-3.03	.127 (>.001)
	Natural log	-2.95	-2.02	.159 (>.001)
Time since diagnosis	Non-transformed	2.54	-1.98	.108 (>.001)
	Square root	-0.07	-2.32	.063 (.200)
	Natural log	-3.38	-0.38	.070 (.200)
AAQ-IDP	Non-transformed	4.62	-0.28	.125 (>.001)
	Square root	2.15	-2.26	.113 (.001)
	Natural log	-0.22	-2.81	.079 (.082)
HADS anxiety	Non-transformed	2.25	-1.47	.078 (.036)
	Square root	-3.48	0.41	.130 (>.001)
	Natural log	-5.65	1.23	.174 (>.001)
HADS depression	Non-transformed	5.28	0.50	.136 (>.001)
	Square root	-0.89	-1.47	.074 (.095)
	Natural log	-2.08	-2.59	.116 (.001)
PGS	Non-transformed	4.51	2.37	.085 (.015)
	Square root	1.71	-0.57	.106 (.002)
	Natural log	-0.68	-1.82	.147 (>.001)
PFP subscale of QRS	Non-transformed	2.93	-2.57	.132 (>.001)
	Square root	-1.95	-2.86	.108 (.001)
	Natural log	-2.70	-3.01	.142 (>.001)
SDQ	Non-transformed	1.06	-0.37	.052 (.200)
	Square root	-2.10	0.27	.087 (.024)
	Natural log	-6.23	5.71	.131 (>.001)
SWLS	Non-transformed	-2.01	-2.98	.104 (.001)
	Square root	-3.75	-1.69	.108 (.001)
	Natural log	-5.69	0.67	.107 (.003)
WEMWBS	Non-transformed	-0.71	-2.88	.047 (.200)
	Square root	-1.98	0.71	.057 (.200)
	Natural log	-5.30	3.63	.083 (.053)

Outliers for each variable were also examined prior to and following data transformations. Transformation eliminated outlying values for each variable. Of the non-transformed variables, outliers were detected in the AAQ, PGS and parent years in education. Each outlier was changed to the next highest plus one or lowest minus one value in the variable data set, depending on the extremity of the value. This process ensured that the outliers maintained their position within the distribution while improving normality. Following this, normality plots were re-checked, however outlier replacement did not significantly improve the normality distributions. Outliers and replacement values can be found in table 3.

Table 3. Outliers

Variable	Outlier value	Replacement value
AAQ -IDP Total	49, 50, 50	39
PGS Total	27, 29, 30	26
WEMWBS Total	17, 18, 19, 20, 21, 22	16

4.3. Descriptive Statistics

4.3.1 The sample

In total, 235 participants returned questionnaires. Nineteen respondents indicated that their child did not have a diagnosed LD/ ASD and were therefore excluded from the study. Of the 216 remaining respondents, 162 were female carers, 53 were male and one did not specify gender. All participants were key carers of children attending an ASN school or base in North Lanarkshire. Tables 4 and 5 outline the demographic and characteristic profile of the sample.

Table 4. Parent demographics

Carer	***N***	**%**		**Marital Status**	***N***	**%**
Mother	151	69.9		Single	34	15.7
Father	51	23.6		Married	125	57.9
Grandmother	9	4.2		Divorced/ Separated	35	16.2
Grandfather	2	.9		Not specified	22	10.2
Sibling	1	.5				
Adoptive/ Foster carer	1	.5				
Aunt	1	.5				
Level of support	***N***	**%**		**Self help accessed?**	***N***	**%**
None	34	15.7		Yes	175	81.0
One-off, assessment	53	24.5		No	33	15.3
Follow-up appointments	114	52.8		Not specified	8	3.7
Not specified	15	6.9				

Table 5. Parent characteristics

	Mean	***SD***	**Range**	**% above clinical cut-off**
Parent age	41.3	6.41	25-57	
Parent years of education	12.1	1.88	9-22	
AAQ-IDP	21.1	9.98	8-50	
HADS Anxiety	8.35	5.03	0-20	B=22.7; C=31.0*
HADS Depression	5.54	4.46	0-19	B=16.7; C=13.9*
PGS	13.43	4.60	7-28	
PFP subscale of QRS	5.32	4.29	0-15	
SDQ	19.15	6.52	3-35	B=13.4; C=66.7*
SWLS	22.87	7.83	5-35	
WEMWBS	45.59	10.73	15-70	

* B= 'Borderline' range, C= 'Caseness' range

The children of the parents in this sample were aged between 50.6 and 223.4 months – approximately 4.2 and 18.6 years of age. The mean age was 135.6 months

– approximately 11.3 years (*SD*=43.90). A summary of the diagnostic profile of the children is provided in table 6.

Table 6. Child diagnoses

Diagnosis	***N***	**%**		**Level of LD**	***N***	**%**
Autism spectrum disorder	65	40.4		Mild	11	6.8
Learning disability	71	44.1		Moderate	56	34.8
LD and ASD	25	15.5		Severe	37	23.0
				Profound	6	3.7
				Unsure/ Missing	51	31.7

4.3.2 Univariate correlation analysis

It was hypothesised that parental acceptance will show a significant correlation with all parental adjustment variables. Due to non-normal distribution within the overall sample, Spearman's correlation coefficients were conducted and examined to determine associations between parental adjustment variables and all independent variables measured on an interval scale, including demographic variables. Dichotomous variables (parent gender, access to self help) were examined using Mann-Whitney tests. Level of LD and level of formal support were represented by ordinal data and a Spearman's rho coefficient was calculated for this variable. The marital status variable was represented by discrete group membership with no underlying continuum. A Kruskal-Wallis test was used to examine the relationship between this variable and all adjustment outcomes. Mann-Whitney test results are displayed in tables 7-8. The Kruskal-Wallis results are displayed in table 9. The correlation matrix is displayed in table 10.

Table 7. Mann-Whitney tests for accessing/ not accessing self help and adjustment variables

Variables	Access self help	*N*	Mean rank	*U*	Sig.
Parent depression	Yes	175	105.24	3016.50	.683
	No	33	100.59		
Parent anxiety	Yes	175	106.69	3271.50	.225
	No	33	92.86		
Parent stress	Yes	175	107.78	3461.50	.069
	No	33	87.11		
Parent satisfaction with life	Yes	175	101.45	2354.50	.092
	No	33	120.67		
Parent wellbeing	Yes	175	102.12	2471.50	.189
	No	33	117.11		

Table 8. Mann-Whitney tests for parent gender and adjustment variables

Variables	Gender	*N*	Mean rank	*U*	Sig.
Parent depression	Female	162	113.81	3351.00	.016*
	Male	53	90.23		
Parent anxiety	Female	162	114.92	3171.50	.004*
	Male	53	86.84		
Parent stress	Female	162	109.84	3995.00	.447
	Male	53	102.38		
Parent satisfaction with life	Female	162	107.58	4361.00	.863
	Male	53	109.28		
Parent wellbeing	Female	162	104.47	4864.50	.146
	Male	53	118.78		

*sig. at p=<.005

Table 9. Kruskal-Wallis test of marital status and adjustment variables

Outcome variable	Marital status	*N*	Mean rank	*df*	*H*	Sig.
Parent depression	Single	34	109.09	2	3.228	.199
	Married	125	92.21			
	Divorce/Sep	35	105.13			
Parent anxiety	Single	34	108.72	2	6.007	.051
	Married	125	90.22			
	Divorce/Sep	35	112.59			
Parent stress	Single	34	109.40	2	2.428	.297
	Married	125	93.21			
	Divorce/Sep	35	101.26			
Parent satisfaction with life	Single	34	99.31	2	5.30	.063
	Married	125	102.61			
	Divorce/Sep	35	77.49			
Parent wellbeing	Single	34	91.35	2	4.998	.082
	Married	125	103.79			
	Divorce/Sep	35	81.01			

Results from the Mann-Whitney tests and Kruskal-Wallis test show that there were no differences in outcome variable between the groups of parents that accessed self-help materials, and those that did not, nor between parents of different marital status. There was a gender difference in anxiety and depression scores, but no gender difference in the other outcome variables.

Table 10. Correlations

	1	2	3	4	5	6	7	8	9	10	11	12	13	14
1 Depression		.690**	.625**	-.511**	-.719**	.620**	.381**	.401**	-.007	-.042	-.017	.189*	.058	-.050
2 Anxiety			.632**	-.511**	-.717**	.643**	.308**	.454**	-.064	-.017	-.055	.128	-.013	-.053
3 Stress				-.585**	-.643**	.613**	.386**	.510**	.079	.050	.062	.216**	.096	-.041
4 Satisfaction with life					.649**	-.481**	-410**	-.388**	-.074	-.147*	-.047	-.128	-.058	.001
5 Wellbeing						-.633**	-.457**	-.349**	-.009	-.046	-.054	-.156*	-.013	.011
6 Acceptance							.391**	.426**	-.029	-.060	-.025	.063	.001	-.013
7 Positive gain								.259**	.100	.118	.146	-.061	-.065	.016
8 Behaviour problems									-.053	-.080	-.294**	.091	.031	-.136
9 Parent age										.296**	.329**	-.011	.133	.062
10 Child age											.641**	.133	-.072	.101
11 Time since diagnosis												.193*	.077	.224**
12 Level of LD													.272**	-.157
13 Formal support														-.030
14 Parent years in education														

* Correlation significant at .05 level (2-tailed)

** Correlation is significant at .01 level (2-tailed)

The data in table 10 show that all dependent variables of anxiety, depression, stress, satisfaction with life and wellbeing correlate significantly and strongly with one another (*p*=<.001). The independent variables found to correlate significantly strongly with these dependent variables are acceptance, positive gain and level of challenging behaviour. Level of LD/ ASD severity was found to correlate moderately to strongly significantly with depression, stress and wellbeing (*p*=<.001-.005). Child age was found to have a moderately significant correlation with satisfaction with

life scores. As acceptance was found to correlate significantly with each of the dependent variables, we can reject the null hypothesis for this univariate analysis.

All variables from the Mann-Whitney tests, and correlations that demonstrated significant relationships with the parental adjustment variables were entered into multiple regression analyses. The variables of 'diagnostic group' and 'school' were re-coded into dummy variables and entered into the regression model in the first and second steps to control for the contribution of these variables to the overall variance in the dependent variables.

4.4. Hypothesis 1: Parental acceptance will account for significant variance in parental psychological adjustment, after controlling for demographic, child-related and parent-related variables known to influence outcomes

4.4.1 Hierarchical multiple regression analysis

For the parental depression dependent variable, the diagnostic group variable was entered into the first step of the model using blockwise entry, followed by the school variable in the second step. The demographic variable (parent gender) was entered into the third step of the model, followed by level of LD/ ASD in the fourth step and level of challenging behaviour (predictors found to account for variance in previous literature) in the fifth step. Positive gains and acceptance were entered in the sixth and seventh steps (the variables of interest).

The R^2 for diagnostic group was .049 ($F_{(df\ 2)}$=4.328, p=.015), and for school was .165 ($F_{(df\ 14)}$=1.539, p=.103), indicating that diagnostic group – but not school group –

contribute significantly to the variance. Parent gender was found to have an R^2= .195 ($F_{(df\ 1)}$=5.779, p=.017), indicating that gender contributes significantly to the variance. Level of LD/ ASD contributed an additional 0.003% (R^2= .198, $F_{(df\ 1)}$=.482, p=.492) of the variance, which was found to be non-significant, level of challenging behaviour and positive gains contributed 12.9% (R^2=.327, $F_{(df\ 1)}$=24.257, p=<.001) and 9.3% (R^2=.420, $F_{(df\ 1)}$=24.257, p=<.001) respectively. After all other predictors were entered into the model, acceptance was found to contribute a significant proportion of the variance, with an R^2 of .547 ($F_{(df\ 1)}$=42.089, p=<.001). Overall, the model accounted for 54.7% of the total variance in parental depression. The adjusted R^2 of .484 is similar in value to the R^2, indicating that cross-validity is good, and that the results can be generalised to the wider population.

For the second dependent variable (parental anxiety), diagnostic group and school were entered into the model in the first and second steps, using blockwise entry. Diagnostic group was found to account for a small and non-significant amount of the variance (R^2=.008, $F_{(df\ 2)}$=.814, p=.445), as was school (R^2=.107, $F_{(df\ 14)}$=1.566, p=.091). The demographic variable that correlated significantly with the dependent variable (in this case, parent gender) was entered into the third step of the model, followed in the fourth step by level of challenging behaviour (predictor found to account for variance in previous literature). In the fifth step, the positive gains variable was entered into the model, followed in the final step by acceptance (the variables of interest in this research question). The R^2 for parent gender was .139 ($F_{(df\ 1)}$=7.473, p=.007), indicating that this contributes 3.3% of the variance. Level of challenging behaviour contributed an additional 20.5% (R^2=.344, $F_{(df\ 1)}$=61.138,

p=<.001), while positive gains contributed 4.6% of the variance (R^2=.390, $F_{(df\ 1)}$=14.813, p=<.001). After all other predictors were entered into the model, acceptance was found to account for a significant proportion of the variance, with an R^2 of .539 ($F_{(df\ 1)}$=62.741, p=<.001). Overall, the model accounted for 53.9% of the total variance in parental anxiety. The adjusted R^2 of .492 is similar in value to the R^2, indicating that cross-validity is good, and that the results can be generalised to the wider population.

For the parental stress dependent variable, diagnostic group and school were entered into the model in the first and second steps, using blockwise entry. Diagnostic group was found to account for a significant proportion of the variance (R^2=.076, $F_{(df\ 2)}$=6.947, p=<.001). School accounted for a non-significant proportion of the variance (R^2=.193, $F_{(df\ 14)}$=1.614, p=.081). Level of LD/ ASD and level of challenging behaviour were entered into the regression model in the third and fourth steps (predictors found to account for variance in previous literature). In the fifth and sixth steps, positive gain and acceptance were entered into the model (variables of interest in this research question). Level of LD/ ASD had an R^2 of .204 ($F_{(df\ 1)}$=2.178, p=.142), accounting for a non-significant proportion of the variance. Level of challenging behaviour was found to contribute an additional 18.1% of the variance (R^2=.385, $F_{(df\ 1)}$=45.413, p=<.001) while positive gains contributed an additional 6.8% of the variance (R^2=.453, $F_{(df\ 1)}$=19.089, p=<.001). After all other predictors were entered into the model, acceptance was found to account for a significant proportion of the variance (R^2=.563 $F_{(df\ 1)}$=38.162, p=<.001). Overall, the model accounted 56.3% of the variance in parent stress. The adjusted R^2 of .505 is

similar in value to the R^2, indicating that cross-validity is good, and that the results can be generalised to the wider population.

For the satisfaction with life dependent variable, diagnostic group and school were entered into the model in the first and second steps, using blockwise entry. Diagnostic group was found to account for 3.3% of the variance (R^2=.033, $F_{(df\ 2)}$=3.663, p=.027). School was found to account for 11.1% of the variance (R^2=.144, $F_{(df\ 14)}$=1.848, p=.034). The demographic predictor found to correlate significantly with the outcome variable (in this case, child age) was entered into the model in the third step. This was found to account for a non-significant proportion of the variance (R^2=.155, $F_{(df\ 1)}$=2.486, p=.116). Level of challenging behaviour, entered in the fourth step of the model, was found to account for 11.8% of the variance, a significant proportion (R^2=.274 $F_{(df\ 1)}$=32.127, p=<.001). Positive gains and acceptance, were added to the model in the fifth and sixth steps. Positive gain predicted an additional 8.5% (R^2=.358, $F_{(df\ 1)}$=25.800, p=<.001). After all other predictors were entered into the model, acceptance was found to account for a significant proportion of the variance (R^2=.418, $F_{(df\ 1)}$=19.936, p=<.001). The overall model accounted for 41.8% of the variance. The adjusted R^2 of .358 is similar in value to the R^2, indicating that cross-validity is good, and that the results can be generalised to the wider population.

For the fifth dependent variable (wellbeing), diagnostic group and school were entered into the model in the first and second steps, using blockwise entry. Level of LD/ ASD and level of challenging behaviour (predictors found to account for

variance in previous literature) were entered into the regression model in the third and fourth steps using, followed by positive gain and finally acceptance (variables of interest in this research question). Diagnostic group was found to contribute a non-significant proportion of the variance (R^2=.027, $F_{(df\ 2)}$=2.339, p=.100). School contributed an additional 15.4 % of the variance (R^2=.181, $F_{(df\ 14)}$=2.097, p=.015). Level of LD/ ASD was not found to contribute significantly to the variance (R^2=.186, $F_{(df\ 1)}$=1.023, p=.313). Level of challenging behaviour accounted for a significant proportion of the variance (R^2=.272, $F_{(df\ 1)}$=38.594, p=.001), while positive gains accounted for an additional 14.6% (R^2=.418, $F_{(df\ 1)}$=38.594, p=<.001) of the variance. After all other predictors were entered into the model, acceptance was found to account for a significant proportion of the variance in parent wellbeing (R^2=.539, $F_{(df\ 1)}$=39.878, p=<.001). Overall, the model was found to predict 53.9% of the variance in parent wellbeing. The adjusted R^2 of .479 is similar in value to the R^2, indicating that cross-validity is good, and that the results can be generalised to the wider population.

4.4.2. Regression diagnostics

In order to ensure that assumptions of normality, linearity, homoscedasticity, predictor independence and lack of multicollinearity are met, regression diagnostics were carried out for each regression model.

- *Multicollinearity*

Multicollinearity within a regression model indicates that two or more predictors are highly correlated. This can become problematic in that significant predictors

may not be identified from others within the model, reducing the predictive validity. Collinearity statistics were examined to ensure that they met suggested criteria. Myers (1990) noted that the integrity of the model may be questioned if the largest variance inflation factor (VIF) is greater than 10. Additionally, Bowerman & O'Connell (1990) suggested that an average VIF value that is significantly greater than one may threaten the model. For each of the five models, the VIF maximum and average values did not present cause for concern. There were no individual values greater than 10, and the average values were found to be close to one. Tolerance statistics were also examined in each regression model, which should be of a value above 0.1 in order to ensure model integrity (Menard, 1995). Again, this criterion was met for each of the cases within the regression models. These findings suggest that multicollinearity is not a problem across the regression models.

Eigenvalues and variance proportions were examined to investigate the distribution of the variance within each model, and the extent to which the majority loading of each independent variable within each regression model is distributed across the dimensions. Across the five regression models, each predictor with a small eigenvalue was found to have a majority of its variance loading on to a different dimension.

The Durbin-Watson statistics for each regression model were examined to ensure that adjacent residuals are not correlated. All values fell close to 2, with a range of 1.84-2.17. As values lower than 1 or higher than 3 are considered problematic, the assumption of independent residuals within the model was upheld.

- *Assumptions of linearity, normality and homoscedasticity*

Plots of residuals, a histogram and normality plots were generated and examined for each regression model to assess for linearity, normality and heteroscedasticity. For each model, the histogram demonstrated that assumptions of normality had been met, while the normal probability plot of standardised residual plot demonstrated acceptable linearity for each model. The scatterplot of standardised residuals for each model showed random scatter patterns, suggesting normally distributed data. Partial plots of the residuals were also examined. These allow for examination of the residuals for the outcome and each of the predictors when both are regressed separately on the remaining predictors. The partial plots also demonstrated random scatter patterns, providing support for the conclusion that the regression models meet the assumptions of normality and homoscedasticity.

- *Influential cases*

The casewise diagnostics were examined for influential cases (those that lie out with the criterion of less than or greater than a value of two). It is reasonable to expect that around 5% will fall out with this range of -2 to +2. Cases with a value greater than 2.5 should represent no more than 1%. The number of cases that fell out with these parameters varied across the five models. The data is summarised in table 11.

Table 11. Influential cases

Regression model	Cases out with parameter	Cases with value >2.5
1. Parent depression	1.7% (*N*=3)	1.1% (*N*=2)
2. Parent anxiety	1.8% (*N*=4)	0.9% (*N*=2)
3. Parent stress	3.4% (*N*=6)	1.7% (*N*=3)
4. Parent satisfaction with life	2.6% (*N*=6)	1.3% (*N*=3)
5. Parent wellbeing	4.0% (*N*=7)	0.5% (*N*=1)

Cook's distance, Mahalanobis distance and centred value leverage were examined visually for each case included in each regression model, to identify any cases that may have an undue influence on the model. According to Cook & Weisberg (1982), Cook's values greater than one should be subject to further examination. Examination of the Cook's distance values revealed that no case had a value greater than one. The average centred leverage value was calculated in each regression model (the number of predictors, plus one, divided by the total *N* for the model). This allowed for examination of the influence of the observed value of the dependent variable over the independent variables. Leverage values with more than twice the average value (Hoaglin & Welsh, 1978), or three times the average value (Stevens, 2002) were noted. Again, the number of cases found to have two or three times the average leverage value varied across the five regression models. Table 12 summarises the data for each model.

Table 12. Centred value leverage

Regression model	CVL average value	Cases with values 2x average	Cases with values 3x average
1. Parent depression	0.04	20	50
2. Parent anxiety	0.03	24	46
3. Parent stress	0.04	34	39
4. Parent satisfaction with life	0.03	52	48
5. Parent wellbeing	0.04	34	28

Mahalanobis distance was also examined. Although data is unavailable for critical cut off, Barnett and Lewis (1978)'s critical values suggest that values above 15 in a sample of 100 with 3 predictors are problematic, while values above 25 in a sample of *N*=500 with 5 predictors would be considered problematic. Using these guidelines, results are presented in table 13.

Table 13. Mahalanobis distances

Regression model	Number of values over 15	Number of values over 25
1. Parent depression	61	30
2. Parent anxiety	40	40
3. Parent stress	41	28
4. Parent satisfaction with life	44	40
5. Parent wellbeing	34	28

DFBeta statistics were examined for each of the predictor variables in each regression model to identify any cases that fall out with +1 to -1, which would indicate large influence of a value on the regression parameters. No values were found that fell out with this range.

The results from the leverage and Mahalanobis statistics across the models suggest that there are a number of potentially influential cases within the regression model. The Cook's distance statistic indicates that these potentially influential may be influencing the models, although most values fall within or close to the maximum parameters. The lack of outliers within the DFBeta statistics in each model provides additional evidence to suggest that the potentially influential cases do not unduly influence any of the models.

4.4.3 Summary of research findings for Hypothesis 1: Parental acceptance will account for significant variance in parental psychological adjustment, after controlling for demographic, child-related and parent-related variables known to influence outcomes

The findings from the univariate correlations and multiple regression analyses indicate that acceptance accounts for between 6 and 14.9 per cent of the variance in the dependent variables of depression, anxiety, stress, satisfaction with life and wellbeing, after accounting for variance predicted by diagnostic group, school, level of LD, challenging behaviour and positive gains. The proportion of variance accounted for by acceptance in each model was found to be significant. Regression diagnostic analysis has indicated that the models satisfy assumptions, therefore we can conclude that the findings from the regressions are likely to be relatively robust.

4.5. Hypothesis 2. Time since diagnosis will account for a significant proportion of the variance in parental psychological adjustment

Examination of the correlations (table 10) shows no correlation between time since diagnosis and the parental adjustment variables. The literature suggests that adjustment in this population of parents may change as they and their child move through significant periods in their life-span (Blacher, 1984). As such, the time since diagnosis variable was plotted against all five outcome variables and examined using line and scatter plots to assess for non-linear relationships. The plots suggested that there were no linear or non-linear relationships between the time since diagnosis variable and any of the outcome variables.

Further examination of the pattern of variance within this data was conducted using means. The time since diagnosis data was re-coded into discrete time periods (zero to two years, two to four years post diagnosis etc). The data was then plotted using line graphs. We must note that the raw scores of each adjustment outcome variable were included in the graph, as standard scores were not available for the measures used. This prevented direct comparison between the scores on the outcome measures. The graphs allowed for observation of any complex patterns in the data, which may be highlighted through the group means. Examination of the graphs showed that the data was not representative of significant relationships. Consequently, we can accept the null hypothesis that there is no significant relationship between time since diagnosis and parental psychological adjustment.

4.6 Hypothesis 3. Informational support to understand their child's needs will account for a significant proportion of the variance in parental psychological adjustment

Examination of correlation coefficients (table 10) reveals that level of professional support does not correlate with any of the parent outcome variables. This suggests that no linear relationships exist between professional support accessed and parental adjustment.

Examination of the Mann-Whitney test data in table 7 demonstrate that there was no significant difference in adjustment between parents who had accessed self help resources, and those that had not. Consequently, we can accept the null hypothesis that there is no significant relationship between support to understand their child's needs and parental psychological adjustment.

4.7 Post hoc analyses

In order to investigate the relationship between time and parental adjustment further, a post hoc Kruskal-Wallis test was carried out to assess parental adjustment in relation to current child age. It was hypothesised that parental psychological adjustment would differ significantly between child age groups. While a longitudinal analysis was out with the scope of this research project, it was anticipated that a cross-sectional analysis of adjustment at different ages would highlight any patterns in the adjustment process through known transition periods (e.g. starting/ leaving

nursery, primary and secondary school). The child age data was re-coded into age groups, each spanning two years, covering the full age range represented in the study. The results of the post hoc Kruskal-Wallis test are shown in table 14.

Table 14. Kruskal-Wallis test of child age and parental adjustment

Outcome variable	Age group of child (years)	*N*	Mean rank	*df*	*H*	Sig.
Parent depression	4-6	27	115.89	4	1.338	.855
	7-9	56	106.47			
	10-12	38	114.58			
	13-15	63	103.04			
	16-18	31	105.90			
Parent anxiety	4-6	27	117.87	4	4.266	.371
	7-9	56	105.60			
	10-12	38	92.11			
	13-15	63	115.84			
	16-18	31	107.29			
Parent stress	4-6	27	110.07	4	2.026	.731
	7-9	56	101.94			
	10-12	38	107.61			
	13-15	63	106.24			
	16-18	31	121.21			
Parent satisfaction with life	4-6	27	110.50	4	7.368	.118
	7-9	56	122.54			
	10-12	38	114.54			
	13-15	63	98.51			
	16-18	31	90.82			
Parent wellbeing	4-6	27	97.98	4	3.561	.469
	7-9	56	120.88			
	10-12	38	106.36			
	13-15	63	104.40			
	16-18	31	102.79			

The findings from the Kruskal-Wallis test indicate that there is no significant effect of child age across the adjustment variables. In other words, the mean scores on

measures of adjustment between the parents of children in different age groups are not significantly different. This supports the null hypothesis that parental adjustment does not differ significantly across the different child age groups.

5. DISCUSSION

The main aim of this research was to investigate the extent to which particular factors influence adjustment in parents of children with LD/ ASD. Based on previous literature, both within and out with the LD/ ASD field, we were interested in evaluating the relative impact of acceptance, time and informational support. The results will be interpreted and discussed in the context of relevant research from the field, and the clinical implications of the findings will be highlighted. Strengths and limitations of the study will then be put forward, before discussing directions for future research

5.1 Interpretation of the results

Hypothesis 1: Parental acceptance will account for significant variance in parental psychological adjustment, after controlling for demographic, child-related and parent- related variables known to influence outcomes

The findings of this study suggest that a parent's acceptance of their child with LD/ ASD contributes significantly to adjustment, as conceptualised by parental depression, anxiety, stress, satisfaction with life and wellbeing. This effect was found even after controlling for other known predictors of adjustment, indicating that the finding is robust. This finding supports previous research into parental adjustment to having a child with LD/ ASD (Lloyd & Hastings, 2008; MacDonald *et al.,* 2010). These studies also found acceptance to predict a significant proportion of the variance in adjustment. This study used a measure of acceptance designed specifically for parents of children with LD/ ASD, adapted and used by MacDonald *et*

al. (2010). Lloyd and Hastings (2008) measured acceptance at a trait level in their study with mothers of children with LD/ ASD. The increased specificity of the measure used in this study increases the validity of the findings.

The regression models demonstrate some differences with respect to the amount of variance predicted by acceptance. The variance predicted by acceptance in the depression, anxiety and wellbeing models was broadly similar (12.7-14.9 per cent), however in the stress model, acceptance predicted 11 per cent, and only 6 per cent in the satisfaction with life regression model after all other variables were entered into the model. This is broadly consistent with other findings from MacDonald *et al.* (2010). This study also found that acceptance predicted six per cent of the additional variance in paternal stress, 21 per cent of the additional variance in paternal depression and 24 per cent of the additional variance in paternal anxiety, after all other predictors had been entered into the regression model. Despite the differences observed in the current research, it was found that the amount of variance predicted by acceptance was statistically significant in each model. This finding is important, not only in consolidating the findings of previous research, but in widening the scope of a specific measure of acceptance, that has previously been used in one published study with fathers only.

Hypothesis 2: Time since diagnosis will account for a significant proportion of the variance in parental psychological adjustment

The findings from this study indicate no significant relationship between time since diagnosis and parental adjustment. As the correlation analysis makes predictions

based on linear relationships, the data were also plotted in order to visually examine the data for patterns. No obvious patterns within the data were observed. These findings provide evidence against the application of stage or linear models of grief to this population. The picture is complicated by the fact that 19 (8 per cent) of the families did not have a diagnostic label for their child's difficulties, removing them from the sample and discounting the adjustment process that may or may not occur in families with no confirmation of condition. Our finding in relation to time since diagnosis has important repercussions, in that it provides evidence against a linear model of parental adjustment, and suggests that adjustment is a complex process that is still not well understood within the literature.

Hypothesis 3: Informational support to understand their child's needs will account for a significant proportion of the variance in parental psychological adjustment

The results of the findings show that level of informational support to help parents understand their child's needs is not a significant predictor of parent psychological adjustment. Similarly, the results suggest that families who access self help resources do not show differential rates of psychological adjustment as compared to parents who do not access these resources. This is a significant finding, in that it provides evidence against the notion that psycho-education about a child's condition is beneficial in alleviating psychological distress (Greaves, 1997; Keen *et al.,* 2010). However, this research did not ask parents to report specific details about the support received. It may be that the support offered is minimal, or

difficult to access, or indeed that the variation inherent in the definition of support has resulted in a diverse and widely heterogeneous sample.

5.2 Theoretical links and clinical implications

The main significant outcome of this study is the finding that parental acceptance of a child with LD/ ASD predicts a significant amount of the variance in parental adjustment, even after substantial variability is accounted for by other known predictors. This is a similar finding to that of MacDonald *et al.* (2010), who also found that acceptance predicted the variance in parental adjustment, as measured by anxiety, depression, stress and positive gains. The findings from the current study also show that parental acceptance is correlated with positive gains, however Lloyd and Hastings (2008) did not find this relationship. Lloyd and Hastings (2008) used a trait measure of parental acceptance, while MacDonald *et al.* (2010) and the current study used the adapted acceptance measure for parents of children with LD/ ASD. The 2008 and 2010 studies used different measures of parental positive gains, however both measures were specific to having a child with LD/ ASD. These findings, and the findings from the current study suggest that acceptance of a child with LD/ ASD is correlated with positive gains, specifically associated with raising the child, while general trait acceptance does not predict positive gains in the same way. This hypothesis is tentative, due to the small literature field, however the findings from the current study indicate that 'acceptance' is not a singular concept, and that parents may be 'accepting' of their lives in the wider sense, while

continuing to feel less accepting in specific areas. The development of specific measures of acceptance is therefore beneficial.

The findings in the current study support the concept of positive gains as a factor in parental adjustment (Hastings & Taunt, 2002). The literature on positive perceptions tells us that a parent of a child with LD/ ASD may hold both positive and negative perceptions of their parent role, child, and family circumstances, and that these constructs may be relatively independent of one another (Altiere & von Klunge, 2009; Hastings & Taunt, 2002; Lloyd & Hastings, 2008). When we consider these findings alongside the multi-faceted status of acceptance, we can begin to think about the process of adjustment as a somewhat fluid concept. We know that certain factors are reliably linked to parental adjustment e.g. level of challenging behaviour (Baker *et al.,* 2003; Quine & Pahl, 1991), and parental material resources (Emerson *et al.,* 2006), however the results of the current study provide evidence to support the notion of other, less stable factors having an influence on adjustment. It seems that a parent's adjustment can vary depending on, amongst other things, the balance of positive and negative perceptions, and the level of acceptance relating to this specific area of their life.

This notion of adjustment as a fluid process may provide further evidence for acceptance-based interventions. The results of the current study suggest that acceptance is a psychological process that is empirically linked to adjustment, and that interventions that target acceptance are likely to be of value to this population of parents. In the ACT theory, acceptance is part of a multi-faceted model that also

includes constructs such as valued living - making commitments to move towards living life in line with values, and cognitive defusion, which encourages the individual to hold their thoughts and beliefs lightly, allowing space to view these from an objective, non-judging, observer stand-point (Hayes *et al.*, 2006). Being mindful of both positive and negative experiences is likely to allow parents the freedom to explore alternative emotional responses, suggesting that mindfulness approaches may represent a useful therapeutic approach for this population. This may also tap into work around values, in terms of helping parents to strengthen their connections to the kind of parents that they would most like to be, thereby facilitating parental behaviour change towards this goal. At the heart of the ACT model is psychological flexibility, which appears to fit well with our hypotheses about parental adjustment as a fluid process. The small but positive evidence base for ACT interventions for parents of children with LD/ ASD offers support to this hypothesis (Blackledge & Hayes, 2006; Singh *et al.,* 2006).

The exploration of the time since diagnosis in the study of parental adjustment has highlighted some areas for discussion. From the findings, it appears that there is no predictable relationship between time since a child received a diagnosis, and parental adjustment. This is in contrast to findings from the wider disability research, for example Kemp *et al.* (1999) found that those recently diagnosed with epilepsy were found to be less well adjusted than chronic patients. Gernstein *et al.* (2009) conducted a longitudinal study of daily parent hassles in parents of children with LD (without ASD) aged three years, and found that mothers reports of daily stress increased significantly over time.

The finding in the current study of no correlation with adjustment and time since diagnosis appears to provide evidence against the notion of early intervention. According to these results, there is no significant difference between adjustment levels of parents who have recently received a diagnosis for their child, and those who have had a diagnosis for up to 16 years. Although this goes against other findings (e.g. Antonak & Livneh, 1992), we must be cautious in comparing our findings to previous research. Past research into time since diagnosis and parent adjustment to disability has predominantly looked at conditions with a medical definition, and relatively defined periods of onset, such as Down syndrome (Flaherty & Glidden, 2000), epilepsy (Kemp *et al.,* 1999) and neonatal conditions (Doucette & Pinelli, 2004). In contrast, a condition such as ASD may have been present since birth, but diagnosed much later in the child's life. This means that parents may have already begun the process of adjustment to their child's condition and grieved the loss of the 'perfect' child, without having had a diagnostic label. In this sense, the point of diagnosis may not be associated with unexpected grief and shock for these families, in the same way that it may be for a family of child with a congenital condition. It is possible that the literature on time and adjustment to medically diagnosed developmental disabilities does not represent the process of adjustment to diagnoses based on clinical judgement, which form the majority of our sample. In this sense, the current study represents a step towards an under-researched area – parental adjustment processes in child conditions that are not medically diagnosed and may not have an observable period of onset. The relative lack of research into the relationship between time since diagnosis and parental

adjustment to non-medically diagnosed disabilities prevents us from drawing further conclusions about this hypothesis at this stage, and further research is needed to begin to define the process of adjustment over time for these parents.

Despite the apparent contradiction with adjustment to disability literature, the current findings fit with the hypothesis that parental adjustment is fluid and flexible. There is some literature to support this, for example Wikler *et al.* (1981) conducted a follow-up questionnaire study with parents of children with LD/ ASD, and found that parents' reports were in line with the 'periodic crisis' or 'chronic sorrow' theory of adjustment (in which parents continue to experience distress at various time points throughout their child's development), as opposed to the 'time-bound grief' theory (in which parents were expected to go through an initial phase of grieving at birth/ diagnosis, after which there would be very little psychological distress). This study simultaneously surveyed social workers, to compare how professionals might anticipate the adjustment process. There were a number of methodological flaws in this study which limits generalisation (it used a small, non-random sample, and the measures used were not standardised) however the findings suggest that workers over-estimate parental maladjustment early in the child's life, and under-estimate later parental maladjustment. The 'chronic sorrow' theory has been supported in other studies of parent's adjustment over time (e.g. Bowes *et al.,* 2009; Hobdell *et al.,* 2007), although studies of higher quality are needed to strengthen the field.

While the lack of observed relationship between adjustment and time since diagnosis supports the notion of varying adjustment over time, our post-hoc analysis of current age and adjustment produced conflicting results. The findings produced no evidence of peaks and troughs in adjustment at known times of transition. This is somewhat confusing, as the literature that supports a fluid and flexible model of adjustment also suggests that particular developmental milestones are linked with a predictable drop in levels of parent adjustment, as parents are reminded of the differences between expectations and experiences e.g. going to primary school, onset of adolescence, leaving secondary school, 21st birthdays (Wikler *et al*., 1981). The results of the current study appear to indicate that there are no specific time points within a child's developmental trajectory that are associated with poorer parental adjustment. However, it is important to note that the current study of current child age and parent adjustment is cross-sectional rather than longitudinal. This means that our findings represent a snap-shot of individual parent adjustment at the time of completing the questionnaires, and limit the scope for comment on patterns over time. Longitudinal studies would allow for within-subjects comparisons, which would provide richer detail about a parent's adjustment process over time and at different developmental milestones.

Overall, the findings from this research are consistent with results from past literature that suggest parent adjustment to a child's LD/ ASD is a complex and fluid concept. While the fluctuating pattern of adjustment has been conceptualised as a normal grieving process (Olshansky, 1962), there is also recognition that services must be available to meet parents' needs to prevent pathology in this population

(Gordon, 2009). It may be that clearly defined developmental periods associated with poorer parent adjustment to a child's LD/ ASD cannot be reliably evidenced due to fluctuation, variation in support, and adjustment definition. This has implications for ensuring that parents can access services when needed.

In looking at parental need for service support, the findings from the current study are difficult to interpret. This study asked parents about their access to support aimed at understanding their child's needs, from professional services or through self help. No relationships were found between level of support accessed and parent adjustment, which appears to suggest that parents' access to informational support is not linked with any of the adjustment outcomes. This is in contrast to findings from intervention literature that show parental mental health is improved through psycho-education and skills training (e.g. Bristol, 1993; Greaves, 1997; Keen *et al.,* 2010). Parents in this study were asked to give a broad indication of the level of support accessed, however they were not asked to specify the quality, overall quantity, frequency or satisfaction with the support. There was also no information on model of intervention, or delivery modality. The findings from the systematic review at the beginning of this project suggest that these factors may influence intervention outcome. Taken together these factors may have resulted in a very heterogeneous group of support recipients, resulting in invalid analysis. There was also no information gathered relating to the timing of any support accessed. Given the potential for adjustment to vary over time, it may be the case that support was accessed at a time when the family were coping well and the family had less investment in the guidance, or alternatively support may have come at a time

when the family were multiply-stressed and therefore less able to utilise guidance effectively. At a local level, the availability of parental support for parents of children with disabilities is sparse and inconsistent. There is no consistently offered intervention pathway for parents of children with LD/ ASD in North Lanarkshire, and few support or intervention groups are available for professionals to refer into. A small number of the schools that participated in the research advised that informal support sessions for parents to meet together had been facilitated through school, however these were not therapeutically driven or overseen.

A large proportion of the parents in this sample reported accessing self help resources (81 per cent). While many of the self help resources produced are of good quality, it may be that parents struggle to find these without effective sign-posting. The results of the earlier systematic review also suggest that self help resources may be less effective than professionally directed interventions (e.g. Keen *et al.,* 2010).

The findings from this research suggest that those who reported accessing no support did not significantly differ from those who accessed varying degrees of support in the adjustment outcomes. While our earlier systematic review highlighted the factors associated with positive outcome for parent support interventions, we still know very little about the factors that prevent a family accessing support, or the circumstances under which supports can be best utilised. This is an area of interest for the future, as the evidence base for parent

interventions is developing, and the extent to which these evidence based supports can be accessed will be important.

Overall, the findings from the current study indicate that support to understand a child's needs is not predictive of parental adjustment, however there are a number of factors that prevent meaningful interpretation of this result. These include lack of knowledge about supports accessed, lack of local provision for families, and variation within the sample in terms of support satisfaction, in addition to unknown levels of existing knowledge and understanding.

5.3 Limitations of the current study

There are a number of methodological limitations which limit the scope of the current research. Participants were recruited to the research regardless of gender. A number of factors influenced this decision, including a wish to be as inclusive as possible, and also a desire to use the adapted measure of acceptance with mothers, which has not been done in the research before. A benefit has been the finding that parental acceptance and positive gains are correlated, a finding that was not significant in Lloyd and Hasting's 2008 study, which used a less sensitive measure of parental acceptance. A disadvantage of including parents of both genders is that the results do not allow for comment on differential adjustment processes between gender. Within the current study, groups based on gender were unequal in number, and the numbers of males and females recruited to the study were not large enough, when split by gender, to reach an acceptable effect size based on calculations of power. These factors mean that generalisations made on the basis of

gender from this sample would not be generalisable to the wider population of parents. Theoretically, we might predict that restricting the sampling criteria to gender would have allowed for greater reliability in predicting the factors that influence adjustment in males and females. Past research has shown adjustment processes to be different for male and female parents (Heller *et al*., 1997; Saloviita *et al*., 2003), and this difference has also been evidenced over time (Doucette & Pinelli*,* 2004; Lloyd & Hastings, 2008). Despite this, the numbers recruited to this study indicate that excluding one gender from the recruitment process would have jeopardised sample size to an extent that effect sizes could have failed to reach the calculated level. Further research would benefit from focusing on differences in adjustment between genders.

The number of years that parents completed in full time education was used as a proxy for socio-economic status (SES) in this research design. This design is consistent with previous research in the field (e.g. Gerstein *et al.,* 2009; Hastings *et al.,* 2002; Lloyd & Hastings, 2009; Trute *et al.,* 2005), however it is recognised that there are other more reliable measures of SES e.g. home postcodes. Previous research in this field that used home postcode data as a proxy for SES found correlations between family deprivation and parental stress, while parental years in education was not found to correlate with any of the outcome variables (Lloyd & Hastings, 2008; MacDonald e*t al.,* 2010).

An alternative to home postcode data may be to use school catchment postcodes as an estimate of SES, however this was not possible in the current study. North

Lanarkshire educational placements are made by matching a child's individual needs to an appropriately resourced North Lanarkshire ASN school, which may not be the ASN school nearest to their home. Although anonymity would have been jeopardised if families were asked for their home postcodes in this research, it is likely that including this data in our analysis would have increased the reliability of the SES variable. Use of an alternative measure of SES within the current study, such as home postcode, may have produced a significant effect of SES on parental adjustment.

In our initial analyses, differences in the adjustment variables were found between parents whose children attended different schools and also in parents of children in different diagnostic groups. These differences resulted in a heterogeneous sample. In order to ensure that heterogeneity did not unduly influence our results, these variables were controlled for in the regression analysis by entering school and diagnostic group into the model before other predictors. Controlling for these factors allows us to report relatively robust findings for the variable of interest – parental acceptance. The finding that parents of children with different diagnoses show differences on the adjustment outcome variables cannot be commented upon further in this study, due to small sample sizes in each group. It will likely be of interest to explore the possibility that parents of children with different diagnoses have different adjustment experiences in future research.

A difficulty in conducting research in this field is defining the concept of adjustment. This project has considered a range of literature on the topic of adjustment, and

used this literature to tailor outcomes that meet the theoretical definition. Despite this, significant discrepancy exists in the definition of what it means to be 'adjusted' to having a child with an LD/ ASD. Factors considered under the umbrella of 'adjustment' in the literature include parent attributions (Armstrong & Dagnan, 2011), personality (Glidden & Schoolcraft, 2003), hope (Lloyd & Hastings, 2009b), parent satisfaction (Dukmak, 2009), sense of competence (Hill & Rose, 2009), and self esteem (Hassal *et al.,* 2005). This variation makes comparisons within the literature problematic. The current study used a number of outcome measures to quantify adjustment. Some, such as the HADS (Zigmond & Snaith, 1983) have been used repeatedly within the field, whereas others such as the wellbeing scale (WEMWBS: Tennant *et al.,* 2007) and the satisfaction with life scale (SWLS: Diener *et al.,* 1985) are relatively new to the field. While this gives opportunity for the consideration of new definitions of adjustment, there is recognition that expansion of the term 'adjustment' has implications for conclusions being drawn from the literature.

A possible limitation within the data analysis is the number of potentially influential cases that were highlighted in the regression diagnostics. While the residuals were found to be normally distributed, and the casewise diagnostics indicated that these cases did not unduly influence the model, it will likely be of benefit that the analysis is replicated in other samples to increase the validity of generalising the findings.

A potential limitation in this study is the use of self-report measures. This has largely been the method of choice for gathering information within this field of

research, as it allows large scale comparisons. Despite this, there are methodological difficulties in this approach, in that self report methods of data gathering can lead to bias. In the field of interventions to support parents of children with LD/ ASD, there are examples of conflicting parent reports and clinician observations (e.g. Roberts *et al.,* 2011). There has also been research to suggest that maternal reports of a child's challenging behaviour can be biased by the mother's emotional state (Najman *et al.,* 2001). Some researchers have attempted to remove the impact of this bias e.g. Erguner-Tekinalp & Akkok (2004) used standardised outcome measures as part of a clinical interview to determine the efficacy of an intervention to support mothers of children with ASD, while Hastings (2003) gathered information about children's challenging behaviour through teacher reports. Including objective methods of data gathering within the current study may have increased the validity of the results by reducing bias.

5.4 Directions for future research

The field of parent adjustment to a child's LD/ ASD is continuing to develop. The current study has highlighted a need for more accurate measures of assessing the impact of informational support on parental adjustment. This has shown positive findings in the intervention literature, however the level of optimum informational support, and the method through which this is best accessed remain unclear. Further research may also focus on the quality of support available, and on the accessibility of this.

Further longitudinal research is needed in order to ascertain the process of adjustment over time. This would allow for development of theoretical models of adjustment that take time into account, which may then provide a framework for optimum service provision to support these parents. While early intervention is generally thought to be of use to parents, findings in the literature suggest that professionals may over-estimate early maladjustment (Wikler *et al.,* 1981). A robust understanding of the factors that influence parent adjustment over time is needed in order to ensure the needs of parents are met when appropriate.

Although research into the differential adjustment processes of male and female parents and carers is developing, no firm conclusions have yet been drawn about which factors vary reliably in adjustment between the genders. As a result, this is an area of research that needs further attention, in order to ensure support needs of both mothers and fathers are met appropriately.

The field would also benefit from continued development of specific outcome measures. This study has highlighted the apparently multi-faceted concept of acceptance, and the research appears to show signs of recognising the process of adjusting to raising a child with LD/ ASD as a unique process. Validation studies of more specific outcome measures will aid in defining the process of parent adjustment, and the factors associated with this in relation to parenting a child with LD/ ASD.

5.5 Conclusions

This study has provided evidence to support the notion that acceptance and positive gains predict significant variance in parent's adjustment to having a child with LD/ ASD. These findings have implications for the development of appropriate interventions to support parents in the adjustment process. The study also explored the impact of relatively under-researched factors within the adjustment literature in this field – time since diagnosis and informational support offered to parents to help them to understand their child's condition and needs. While there were no significant findings from this exploratory analysis, a number of hypotheses were considered based on previous research that may account for the observed lack of significance. Further research into the time and support variables may assist in theoretical framework development, which will ultimately enhance our understanding of the interventions that can best support this population of parents throughout the process of adjustment.

6. JOURNAL ARTICLE

Factors that influence parental adjustment to having a child with a learning disability

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6.1. Abstract

Background This study aims to add to the research into the factors influencing adjustment to parenting a child with a learning disability (LD) and/or autism spectrum disorder (ASD). In particular, parental acceptance, time since diagnosis and the influence of informational support to understand a child's individual needs will be explored.

Method Two hundred and sixteen parents of children aged 4-19 participated in a questionnaire study, conducted through local additional support needs (ASN) schools and bases. Measures of psychological adjustment were gathered alongside measures of acceptance and demographic information.

Results Along with other variables, psychological acceptance was found to account for significant variance in parental adjustment. There were no observed relationships between level of support to understand child needs and parent adjustment.

Conclusions The results have implications for the understanding of the role of acceptance in parent adjustment. Implications for intervention development and future research directions are discussed, in addition to the methodological limits of the study.

Keywords Learning disability, autism spectrum disorders, parent adjustment, acceptance, informational support

6.2. Introduction

There is significant research evidence to suggest that parenting a child with LD/ ASD is highly stressful (e.g. Byrne & Cunningham 1985; Olsson & Hwang 2008) and that parents of children with LD/ ASD experience more psychological distress than parents of neuro-typical children (Dyson 1993). Despite this, the literature also tells us that there is wide variation in psychological adjustment within this population of parents (Frey e*t al.* 1989; Quine & Pahl 1991).

Conceptually, adjustment has been defined as 'coming to terms with pain or limitations…and an attempt to resolve the dual demands of symptoms and society (p.156)' (Radley 1994). This definition suggests that it is not only factors associated with illness or disability that influence adjustment, but also the social context within which these symptoms occur. Consequently, there has been some research interest in recent years in explaining the variance in adjustment. The research into factors that account for the variance in parent adjustment to a child's LD/ ASD is broad and varied, but can be roughly distinguished into three areas - contextual family factors, such as poverty and parental resources (Emerson *et al.* 2006), child characteristics, such as level of challenging behaviour (Baker *et al.* 2003; Quine & Pahl 1991) and parent characteristics, in particular parental cognitive factors.

Within the past 20 years, parental cognitive factors have begun to be increasingly analysed in relation to adjustment, within the LD/ ASD literature. Research into parental locus of control (Lloyd & Hastings 2009a), parental self-efficacy (Hastings & Brown 2002) and parental acceptance (Lloyd & Hastings 2008) appear to

demonstrate that parental cognitions are associated with well-being and adjustment, in both cross-sectional and longitudinal research designs (Lloyd & Hastings 2009a). These findings are important and promising, as cognitive factors are amenable to psychological intervention, suggesting that therapeutic routes may be of benefit to this population.

Psychological acceptance is a concept that has recently attracted interest within the field of disability research. Previously, acceptance was largely studied within the fields of physical health and mental health. McCracken and Ecclestone (2003) found that acceptance of chronic pain was associated with reduced depression, pain-related anxiety, and disability. In a study investigating acceptance of disability in a sample of paraplegic participants, those with high levels of acceptance reported higher self-esteem and quality of life than those with low or moderate levels of acceptance (Ferrin *et al.* 2011). Moving into the acceptance of LD/ ASD field, Lloyd and Hastings (2008) found that mothers who were generally more accepting reported fewer psychological adjustment problems in relation to raising a child with LD/ ASD. MacDonald *et al.* (2010) found that acceptance in fathers of children with LD/ ASD partially mediates the impact of behaviour problems upon paternal stress, anxiety and depression. This study used an adapted version of the Acceptance and Action Questionnaire II (AAQ-II: Bond *et al.* 2011), in order to measure parental acceptance to a child's LD/ ASD specifically. Although not longitudinal, the results of this study add support to the existing literature in the area of acceptance of disability, by measuring levels of acceptance in relation to a specific life stressor. This allows for more specific investigation of parental acceptance of a child's LD/

ASD, which may differ from a parent's rating of general acceptance that has previously been used in the adjustment literature.

Time since diagnosis is a concept that has rarely been studied in relation to parental adjustment to a child's LD/ ASD. Some research in the field of adjustment to physical and chronic illness has shown adjustment to be positively correlated with time since onset (e.g. Kovacs *et al.* 1986). This supports the notion of an initial process of grief, followed by a gradual adaptation, and has theoretical underpinnings in the models of grief and loss e.g. Kubler-Ross' stages of grief model (1969). This linear model of grief is not supported by all e.g. Johnson and Meltzer (2002) suggest that the process of adjustment may not be linear, and that the role of developmental characteristics of chronic conditions must be acknowledged in this process, in addition to child physical and cognitive development. As an alternative to the time-bound grief theory of adjustment, Olshansky (1962) put forward a hypothesis that parent's adjustment to their child's disability may be characterised by periodic sadness throughout the developmental lifespan. The author characterised this as a normal process, and suggested that these parents experienced 'peaks and troughs' at specific developmental milestones. Increased knowledge about the process of adjustment over time may assist in appropriate service provision for these parents.

Some contextual factors, including availability of social and spousal support (Bristol *et al.* 1988), respite (Skok *et al.* 2006), and family income (Singhi *et al.* 1990, Farmer *et al.* 2004) have been researched in the field of parental adjustment to a child's LD/

ASD. There has been relatively little research into the impact of self help and informational support from services, e.g. the impact of disorder specific information on parental adjustment (Bailey & Simeonsson 1988), and signposting to relevant informational support services (Farmer *et al.* 2004). The relationship between increased understanding of a child's needs and parent adjustment is not well understood, and further research is needed.

Based on previous research findings in relation to parental adjustment and the factors found to influence this, the focus of the current research is as follows:

Hypothesis 1: Parental acceptance will account for significant variance in parental psychological adjustment, after controlling for demographic, child-related and parent-related variables known to influence outcomes

Hypothesis 2: Time since diagnosis will account for a significant proportion of the variance in parental psychological adjustment

Hypothesis 3: Informational support to understand their child's needs will account for a significant proportion of the variance in parental psychological adjustment

6.3. Method

6.3.1. Participants

Of the 235 respondents, 19 stated that their child did not have a diagnosis of LD/ ASD and were excluded from the study, resulting in a total of 216 participants. 162 were female carers, 53 were male and one did not specify gender. All participants were key carers of children attending an ASN school or base in North Lanarkshire.

Formulae detailed in Green (1991) to evaluate sample size in multiple regression analysis were consulted in calculating sample size. Setting alpha at 0.5, the traditional level of probability, and taking into account the number of independent variables in this study, we calculated that a sample size, based on a conservative estimate of effect size (medium) would be between 119 and 139.

Tables 1 and 2 outline the demographic and characteristic profile of the sample.

Table 1. Parent demographics

Carer	***N***	**%**		**Marital Status**	***N***	**%**
Mother	151	69.9		Single	34	15.7
Father	51	23.6		Married	125	57.9
Grandmother	9	4.2		Divorced/ Separated	35	16.2
Grandfather	2	.9		Not specified	22	10.2
Sibling	1	.5				
Adoptive/ Foster carer	1	.5				
Aunt	1	.5				
Level of support	***N***	**%**		**Self help accessed?**	***N***	**%**
None	34	15.7		Yes	175	81.0
One-off, assessment	53	24.5		No	33	15.3
Follow-up appointments	114	52.8		Not specified	8	3.7
Not specified	15	6.9				

Table 2. Parent characteristics

	Mean	*SD*	Range	% above clinical cut-off
Parent age	41.3	6.41	25-57	
Parent years of education	12.1	1.88	9-22	
AAQ-IDP	21.1	9.98	8-50	
HADS Anxiety	8.35	5.03	0-20	B=22.7; C=31.0*
HADS Depression	5.54	4.46	0-19	B=16.7; C=13.9*
PGS	13.43	4.60	7-28	
PFP subscale of QRS	5.32	4.29	0-15	
SDQ	19.15	6.52	3-35	B=13.4; C=66.7*
SWLS	22.87	7.83	5-35	
WEMWBS	45.59	10.73	15-70	

*B= Borderline range, C= Caseness range

The children of the parents in this sample were aged between 50.6 and 223.4 months – approximately 4.2 and 18.6 years of age. The mean age was 135.6 months – approximately 11.3 years (*SD*=43.90). A summary of the diagnostic profile of the children is provided in table 3.

Table 3. Child diagnoses

Diagnosis	*N*	%		Level of LD	*N*	%
Autism spectrum disorder	65	40.4		Mild	11	6.8
Learning disability	71	44.1		Moderate	56	34.8
LD and ASD	25	15.5		Severe	37	23.0
				Profound	6	3.7
				Unsure/ Missing	51	31.7

6.3.2. Measures

The following five scales were used to represent parental adjustment.

The Hospital Anxiety and Depression Scale (HADS: Zigmond & Snaith 1983) was used to measure parental mental health. Past research using the HADS with mothers of children with LD/ ASD has shown that the scale maintains good reliability (Cronbach's alpha coefficient in excess of 0.8) (Hastings & Brown 2002). The HADS has been used extensively in community populations despite original development for hospital populations (MacDonald *et al.* 2010). Within the present study, the HADS achieved Cronbach's alpha of 0.84 (depression) and 0.86 (anxiety).

The Parent and Family Problems sub-scale of the Questionnaire on Resources and Stress Friedrich short form (PFP of QRS) (Friedrich *et al.* 1983) was used as a measure of parenting stress. Previous research with parents of children with LD/ ASD used an amended version of this scale, removing five items that have been shown to constitute a robust measure of depression in parents of children with LD/ ASD (Glidden & Floyd 1997). More recent research has found the scale to have a correlation coefficient of between 0.86 (Lloyd & Hastings 2008) and 0.90 (MacDonald *et al.* 2010) for a total score derived from the remaining items. In the present study, the PFP of QRS achieved Cronbach's alpha of 0.88.

The Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS: Tennant *et al.* 2007) is a 14-item measure relating to different aspects of positive mental wellbeing. It has good internal validity, and has been demonstrated to have a Cronbach's alpha of 0.91 in a population sample during development (Tennant *et al.* 2007). The WEMWBS has been shown to have a significantly high correlation with other

measures of affect and wellbeing e.g. Scales of Psychological Wellbeing (r=0.74, p=<.001), and the Positive and Negative Affect Scales (r=0.71, p=<.001) (Tennant *et al.* 2007). Within the present study, the WEMWBS achieved Cronbach's alpha of 0.94.

The Satisfaction with Life Scale (SWLS: Diener *et al.* 1985) was also used as a measure of parental adjustment. This 5-item scale has been developed to provide a discrete measure of life satisfaction, and has been found to have good internal consistency (Diener *et al.* 1995). Within the present study, the SWLS achieved Cronbach's alpha of 0.89. Satisfaction with life is a concept that has been interpreted as a construct of psychological adjustment within disability research (e.g. Dahlbeck & Lightsey 2008), however it does not appear to have been widely researched in relation to a parent's psychological adjustment.

The following measures were used to represent predictor variables.

The Strengths and Difficulties Questionnaire (SDQ: Goodman 1997) is a brief, well-validated measure of clinically significant challenging behaviour in children. This scale was used as a measure of child challenging behaviour. Previous research suggests that good levels of reliability are maintained when used with a population of parents of children with LD/ ASD, e.g. Cronbach's alpha coefficient of 0.88 (Lloyd & Hastings 2009a). In the present study, the SDQ achieved Cronbach's alpha of 0.71.

The Positive Gains Scale (Pit-Ten Cate 2003) has been used in previous research as a measure of positive experiences associated with raising a child with LD/ ASD (MacDonald *et al.* 2010). The scale consists of five questions that assess perceived parental benefit of raising a child with LD/ ASD, and two questions relating to family gains. Preliminary research suggests that the scale has face and content validity, and has been assessed as having a Cronbach's alpha of 0.79 (Pit-ten Cate 2003) and 0.80 (MacDonald *et al.* 2010). In the present study, the PGS achieved Cronbach's alpha of 0.80.

The 'AAQ-Intellectual Disability Parent' scale (MacDonald *et al.* 2010) is an adapted version of the Acceptance and Action Questionnaire-II (AAQ-II: Bond *et al.* 2011). This adapted, eight item scale has been developed and used by MacDonald *et al.* (2010), in their study of fathers' acceptance in a clinical sample. It was found to have a Cronbach's alpha coefficient of 0.80. This is a specific measure of acceptance in relation to parenting a child with LD/ ASD, as opposed to a general measure of acceptance, which has historically been used in this research field. In the present study, the AAQ-IDP achieved Cronbach's alpha of 0.85.

A questionnaire was used to gather parent demographic information, and information on child's age at diagnosis, diagnostic labels, severity of disability and access to informational support to understand their child's needs.

6.3.3. Procedure

Participants completed questionnaires that were distributed by the schools and returned anonymously.

Ethical approvals were granted by the University of Edinburgh and by the Local Education Authority.

6.4. Results

Univariate analyses were used to select predictors for regression analysis. All variables, with the exception of parent age, SDQ and wellbeing were significantly skewed. Data transformations were not successful in normalising the data. It was hypothesised that the univariate analyses would demonstrate a significant correlation between parental acceptance and all of the parental adjustment variables. Spearman's correlation was used to examine the relationships between predictor variables, demographic variables, and outcome variables, and Mann-Whitney tests were used to examine the effect of dichotomous predictors on outcomes. A Kruskal-Wallis test examined relationships between marital status and outcome variables. Mann-Whitney test results are displayed in tables 4-5. The Kruskal-Wallis test is displayed in table 7. The correlation matrix is displayed in table 8. Independent variables found to correlate significantly with dependent variables were entered into a multiple regression analysis. Heterogeneity within the sample was controlled for by entering 'school' and 'diagnostic group' variables into the regression model.

Table 4. Mann-Whitney test for accessing/ not accessing self help and adjustment variables

Variables	Access self help	*N*	Mean rank	*U*	Sig.
Parent depression	Yes	175	105.24	3016.50	.683
	No	33	100.59		
Parent anxiety	Yes	175	106.69	3271.50	.225
	No	33	92.86		
Parent stress	Yes	175	107.78	3461.50	.069
	No	33	87.11		
Parent satisfaction with life	Yes	175	101.45	2354.50	.092
	No	33	120.67		
Parent wellbeing	Yes	175	102.12	2471.50	.189
	No	33	117.11		

Table 5. Mann-Whitney test for parent gender and adjustment variables

Variables	Gender	*N*	Mean rank	*U*	Sig.
Parent depression	Female	162	113.81	3351.00	.016*
	Male	53	90.23		
Parent anxiety	Female	162	114.92	3171.50	.004*
	Male	53	86.84		
Parent stress	Female	162	109.84	3995.00	.447
	Male	53	102.38		
Parent satisfaction with life	Female	162	107.58	4361.00	.863
	Male	53	109.28		
Parent wellbeing	Female	162	104.47	4864.50	.146
	Male	53	118.78		

*sig. at p=<.005

Table 6. Kruskal-Wallis test of marital status and adjustment

Outcome variable	Marital status	*N*	Mean rank	*df*	*H*	Sig.
Parent depression	Single	34	109.09	2	3.228	.199
	Married	125	92.21			
	Divorce/Sep	35	105.13			
Parent anxiety	Single	34	108.72	2	6.007	.051
	Married	125	90.22			
	Divorce/Sep	35	112.59			
Parent stress	Single	34	109.40	2	2.428	.297
	Married	125	93.21			
	Divorce/Sep	35	101.26			
Parent satisfaction with life	Single	34	99.31	2	5.30	.063
	Married	125	102.61			
	Divorce/Sep	35	77.49			
Parent wellbeing	Single	34	91.35	2	4.998	.082
	Married	125	103.79			
	Divorce/Sep	35	81.01			

Table 7. Correlations

	1	2	3	4	5	6	7	8	9	10	11	12	13	14
1 Depression		.690**	.625**	-.511**	-.719**	.620**	.381**	.401**	-.007	-.042	-.017	.189*	.058	-.050
2 Anxiety			.632**	-.511**	-.717**	.643**	.308**	.454**	-.064	-.017	-.055	.128	-.013	-.053
3 Stress				-.585**	-.643**	.613**	.386**	.510**	.079	.050	.062	.216**	.096	-.041
4 Satisfaction with life					.649**	-.481**	-410**	-.388**	-.074	-.147*	-.047	-.128	-.058	.001
5 Wellbeing						-.633**	-.457**	-.349**	-.009	-.046	-.054	-.156*	-.013	.011
6 Acceptance							.391**	.426**	-.029	-.060	-.025	.063	.001	-.013
7 Positive gain								.259**	.100	.118	.146	-.061	-.065	.016
8 Behaviour problems									-.053	-.080	-.294**	.091	.031	-.136
9 Parent age										.296**	.329**	-.011	.133	.062
10 Child age											.641**	.133	-.072	.101
11 Time since diagnosis												.193*	.077	.224**
12 Level of LD													.272**	-.157
13 Formal support														-.030
14 Parent years in education														

** Correlation is significant at .01 level (2-tailed)

* Correlation is significant at .05 level (2-tailed)

The data in table 8 show that all dependent variables correlate significantly strongly with one another (*p*=<.001). The independent variables found to correlate significantly strongly with these dependent variables are acceptance, positive gain and level of challenging behaviour. Level of LD/ ASD severity was found to correlate moderately to strongly significantly with the depression, stress and wellbeing variables (*p*=<.001-.005). Child age was found to have a moderately significant correlation with satisfaction with life scores. Time since diagnosis did not correlate

significantly with any of the outcome variables. As acceptance was found to correlate significantly with each of the dependent variables, we can reject the null hypothesis for this univariate analysis.

Results from the Mann-Whitney tests showed that gender correlated significantly with the depression and anxiety outcome variables. Female parents scored significantly higher on measures of depression symptoms than male parents. Parental marital status and access/ no access to self help were not found to have significant relationships with any of the outcome variables.

Hierarchical multiple regression analysis

The diagnostic group and school variables were entered into the initial steps of the model using blockwise entry. The demographic variables (e.g. parent gender, child age) were entered into the hierarchical regression model in the following steps. These variables were followed by all significant correlates that are known predictors from previous research (e.g. level of LD/ ASD, level of challenging behaviour). The variables of interest (positive gains and acceptance) were added to the model at the final stages.

A summary of the findings from the regression models can be found in tables 8-12.

Table 8. Regression model (parent depression)

Model		Standardised Beta	t	Sig	R^2	*F*	*p*
1	Diagnostic group	.018-.227	.220-2.810	.006-.826	.049	4.328	.015
2	Diagnostic group	.085-.192	.657-2.260	.025-.512	.165	1.539	.103
	School	-.192-.129	-2.22-1.49	.028-.650			
3	Diagnostic group	.088-.206	.697-2.44	.015-.487	.195	5.779	.017
	School	-.185-.177	-1.78-1.55	.017-.688			
	Parent gender	-.185	-2.404	.017			
4	Diagnostic group	.88-.198	.692-2.32	.021-.490	.198	.482	.489
	School	-.180-.138	-2.32-1.48	.021-.660			
	Parent gender	-.180	-2.323	.021			
	Level of LD	.057	.649	.489			
5	Diagnostic group	.011-.056	.094-.679	.489-.925	.327	29.158	.001
	School	-.132-.406	-2.37-1.14	.001-.929			
	Parent gender	-.169	-2.37	.019			
	Level of LD	.034	.442	.659			
	Challenging behaviour	.406	5.400	.001			
6	Diagnostic group	-.007-.041	-.064-.532	.595-.949	.420	24.256	.001
	School	-.112-.133	-1.84-1.36	.104-.908			
	Parent gender	-.189	-2.84	.005			
	Level of LD	.017	.239	.811			
	Challenging behaviour	.295	4.00	.001			
	Positive gains	.340	4.92	.001			
7	Diagnostic group	.024-.063	.243-.925	.356-.808	.547	42.089	.001
	School	-.089-.088	-1.36-1.32	.165-.757			
	Parent gender	-.156	-2.70	.008			
	Level of LD	.052	.828	.409			
	Challenging behaviour	.107	1.49	1.37			
	Positive gains	.186	2.83	.005			
	Acceptance	.464	.464	.001			

Dependent variable: Parent depression

Table 9. Regression model (parent anxiety)

Model		Standardised Beta	t	Sig	R^2	*F*	*p*
1	Diagnostic group	.073-.082	.992-1.11	.266-.322	.008	.814	.445
2	Diagnostic group	.056-.069	.583-.723	.471-.561	.107	1.566	.091
	School	-.168-.094	-2.35-1.27	.036-.952			
3	Diagnostic group	.059-.066	.563-.774	.440-.574	.139	7.473	.007
	School	-1.74-.085	-2.73-1.17	.014-.873			
	Parent gender	-.185	-2.73	.007			
4	Diagnostic group	-.007-.130	-.066-1.83	.068-.947	.344	61.138	.001
	School	-.192-.061	-3.11-.969	.002-.863			
	Parent gender	.161	-2.71	.007			
	Challenging behaviour	.517	7.81	.001			
5	Diagnostic group	-.010--.152	-.098-2.21	.028-.922	.390	14.813	.001
	School	-.170-.092	-2.96-1.47	.003-.965			
	Parent gender	-.170	-2.95	.004			
	Challenging behaviour	.440	6.57	.001			
	Positive gains	.240	3.84	.001			
6	Diagnostic group	-.001-.116	-.015-1.19	.056-.988	.539	62.741	.001
	School	-.142-.077	-2.71.814	.007-.925			
	Parent gender	-.146	-2.91	.004			
	Challenging behaviour	.263	4.20	.001			
	Positive gains	.081	1.40	.160			
	Acceptance	.484	7.92	.001			

Dependent variable: Parent anxiety

Table 10. Regression model (parent stress)

Model		Standardised Beta	t	Sig	R^2	*F*	*p*
1	Diagnostic group	.106-.295	1.33-3.72	.001-.183	.076	6.947	.001
2	Diagnostic group School	.124-.283 -.152-.139	.985-3.39 -1.79-1.60	.001-.326 .074-.708	.193	1.614	.081
3	Diagnostic group School Level of LD	.124-.267 -.134-.115 .121	.983-3.19 -1.56-1.35 1.47	.002-.327 .119-.965 .142	.204	2.178	.142
4	Diagnostic group School Level of LD Challenging behaviour	.033-.100 -.140-.102 .091 .481	.294-1.28 -2.06-1.37 .212 .001	.199-.769 .044-.878 .212 .001	.385	45.413	.001
5	Diagnostic group School Level of LD Challenging behaviour Positive gains	.017-.086 -.118-.116 .079 .387 .291	.160-1.16 -1.64-1.58 1.15 5.46 4.36	.247-.873 .110-.779 .246 .001 .001	.453	19.089	.001
6	Diagnostic group School Level of LD Challenging behaviour Positive gains Acceptance	.046-.108 -.084-.085 .112 .214 .148 .430	.486-1.63 -1.43-1.33 1.80 3.08 2.29 6.17	.105-.630 .114-.982 .073 .002 .023 .001	.563	38.162	.001

Dependent variable: Parent stress

Table 11. Regression model (parent satisfaction with life)

Model		Standardised Beta	t	Sig	R^2	*F*	*p*
1	Diagnostic group	-.097--.194	-1.34-2.68	.008-.180	.033	3.663	.027
2	Diagnostic group	-.099--.182	-.857-2.40	.017-.392	.144	1.848	.034
	School	-.122-.133	-1.62-1.77	.005-.890			
3	Diagnostic group	-.104--.171	-.889-2.25	.025-.370	.155	2.486	.116
	School	.006--.157	-1.88-2.26	.061-.938			
	Child age	-.154	-1.57	.116			
4	Diagnostic group	-.025-.049	-.337-.455	.649-.736	.274	32.127	.001
	School	-.098-.172	-1.31-2.55	.011-.920			
	Child age	-.182	-2.00	.046			
	Challenging behaviour	-.393	-5.66	.001			
5	Diagnostic group	-.044-.002	-.436-.035	.663-.972	.358	25.800	.001
	School	-.136-.156	-1.83-2.50	.013-.949			
	Child age	-.146	-1.70	.091			
	Challenging behaviour	-.289	-4.21	.001			
	Positive gains	-.325	-5.07	.001			
6	Diagnostic group	-.022--.049	-.328-.506	.614-.743	.418	19.936	.001
	School	.084-.140	-1.56-2.30	.022-.980			
	Child age	-.132	-1.60	.111			
	Challenging behaviour	-.176	-2.51	.013			
	Positive gains	-.225	-3.45	.001			
	Acceptance	-.306	-4.46	.001			

Dependent variable: Parent satisfaction with life

Table 12. Regression model (parent wellbeing)

Model		Standardised Beta	t	Sig	R^2	*F*	*p*
1	Diagnostic group	-.065--.176	-2.16-.799	.032-.426	.027	2.339	.100
2	Diagnostic group School	-.150-.169 -.158-.200	-1.32-1.79 -1.87-2.55	.075-.187 .012-.785	.181	2.097	.015
3	Diagnostic group School Level of LD	-.145-.171 -.151-.165 -.084	.983-3.19 -1.56-1.35 -1.012	.002-.327 .119-.965 .313	.186	1.023	.313
4	Diagnostic group School Level of LD Challenging behaviour	-.025--.106 -.131-.105 -.063 -.330	-.294-.869 -1.59-3.14 -.800 -4.25	.386-.769 .002-.974 .426 .001	.272	18.071	.001
5	Diagnostic group School Level of LD Challenging behaviour Positive gains	.-.003--.082 -.139-.185 -.046 -.192 -.427	-.042-.756 -1.71-.830 -.656 -2.632 -6.214	.452-.967 .007-.556 .513 .009 .001	.418	38.594	.001
6	Diagnostic group School Level of LD Challenging behaviour Positive gains Acceptance	-.113-.027 -.126-.163 -.080 -.011 -.276 -.452	-1.15-.394 -1.92-2.69 -1.262 -.157 -4.194 -6.315	.250-.694 .008-.919 .209 .876 .001 .001	.539	39.878	.001

Dependent variable: Parent wellbeing

Regression diagnostics were carried out for each regression model. These revealed that assumptions of normality, linearity, homoscedasticity, predictor independence and lack of multicollinearity were met, therefore the regression models can be considered valid.

As no linear relationship between time since diagnosis and outcome variables was found in the correlation analysis, a post-hoc Kruskal-Wallis test was carried out to examine current child age and adjustment variables, in order to test for patterns in adjustment between parents of children of different ages. This would allow for

comment on parental adjustment at different developmental milestones, examining evidence for the 'peaks and troughs' model of adjustment over time (Olshansky 1962). There were no significant differences in adjustment between groups of parents. The findings are summarised in table 13.

Table 13. Kruskal-Wallis test of child age and adjustment

Outcome variable	Age group of child (years)	*N*	Mean rank	*df*	*H*	Sig.
Parent depression	4-6	27	115.89	4	1.338	.855
	7-9	56	106.47			
	10-12	38	114.58			
	13-15	63	103.04			
	16-18	31	105.90			
Parent anxiety	4-6	27	117.87	4	4.266	.371
	7-9	56	105.60			
	10-12	38	92.11			
	13-15	63	115.84			
	16-18	31	107.29			
Parent stress	4-6	27	110.07	4	2.026	.731
	7-9	56	101.94			
	10-12	38	107.61			
	13-15	63	106.24			
	16-18	31	121.21			
Parent satisfaction with life	4-6	27	110.50	4	7.368	.118
	7-9	56	122.54			
	10-12	38	114.54			
	13-15	63	98.51			
	16-18	31	90.82			
Parent wellbeing	4-6	27	97.98	4	3.561	.469
	7-9	56	120.88			
	10-12	38	106.36			
	13-15	63	104.40			
	16-18	31	102.79			

6.5. Discussion

Hypothesis 1: Parental acceptance will account for significant variance in parental psychological adjustment, after controlling for demographic, child related and parent related variables known to influence outcomes

The findings of this study suggest that a parent's acceptance of their child with LD/ ASD contributes significantly to adjustment. This finding supports previous research into parental adjustment to having a child with LD/ ASD (Lloyd & Hastings 2008; MacDonald *et al.* 2010). These studies also found acceptance to predict a significant proportion of the variance in adjustment. This study used a measure of acceptance designed specifically for parents of children with LD/ ASD, adapted and used by MacDonald *et al.* (2010). Lloyd and Hastings (2008) measured acceptance at a trait level in their study with mothers of children with LD/ ASD. The increased specificity of the measure used in this study increases the validity of the findings.

In the analyses for each of the measures of adjustment, acceptance was found to account for a significant amount of the variance after other known predictors had been entered into the regression model. In addition to consolidating the findings of previous research, the findings of the current study provide evidence for the use of a specific measure of acceptance, which has previously been used in one published study with fathers only. The results in relation to acceptance and adjustment are important, as they highlight the role of parental acceptance in adjustment to a child's disability, which has implications for acceptance based interventions for these parents.

In the acceptance and commitment therapy (ACT) theory, acceptance is part of a multi-faceted model that also includes constructs such as valued living - making commitments to move towards living life in line with values, and cognitive defusion, which encourages the individual to hold their thoughts and beliefs lightly, allowing space to view these from an objective, non-judging, observer stand-point (Hayes *et al.* 2006). The results of the regression analysis demonstrate that parental ability to identify positive gains in relation to raising their child with LD/ ASD is also predictive of adjustment. Being mindful of both positive and negative experiences of parenting is likely to allow parents the freedom to explore alternative emotional responses, suggesting that mindfulness approaches may be beneficial for this population. This may also tap into work around values, in terms of helping parents to strengthen their focus on the positive aspects of their role. The small but positive evidence base for ACT interventions for parents of children with LD/ ASD offers support to this hypothesis (Blackledge & Hayes 2006; Singh *et al.* 2006).

The findings also show that level of support accessed by parents to assist in understanding their child's need is not a significant predictor of parent psychological adjustment. This provides evidence against the notion that psycho-education about a child's condition is beneficial in alleviating psychological distress (Greaves 1997; Keen *et al.* 2010). However, the current study did not ask parents to report specific details about the support received e.g. quality, overall quantity, frequency or satisfaction with the support. There was also no information on model of intervention accessed, or delivery modality. Taken together these factors may

have resulted in a very heterogeneous group of support recipients, resulting in invalid analysis.

A large proportion of the parents in this sample reported accessing self help resources (81 per cent). While many of the self help resources produced are of good quality, it may be that parents struggle to find these without effective sign-posting. Some studies (e.g. Keen *et al.* 2010) suggest that self help resources may be less effective than professionally directed interventions.

A significant outcome of this study is the finding that parental acceptance of a child with LD/ ASD predicts a significant amount of the variance in parental adjustment. This is a similar finding to that of MacDonald *et al.* (2010), who also found that acceptance predicted the variance in parental adjustment, as measured by anxiety, depression, stress and positive gains. The findings from the current study also show that parental acceptance is correlated with positive gains, however Lloyd and Hastings (2008) did not find this relationship. Lloyd and Hastings (2008) used a trait measure of parental acceptance, while MacDonald *et al.* (2010) and the current study used the adapted acceptance measure for parents of children with LD/ ASD. These findings, and the findings from the current study suggest that acceptance of a child with LD/ ASD is correlated with positive gains, specifically associated with raising the child, while general trait acceptance does not predict positive gains in the same way. This hypothesis is tentative, due to the small literature field, however it indicates that 'acceptance' is not a singular concept, and that parents may be 'accepting' of their lives in the wider sense, while continuing to feel less

accepting in specific areas. The development of specific measures of acceptance is therefore beneficial.

Hypothesis 2: Time since diagnosis will account for a significant proportion of the variance in parental psychological adjustment

While the lack of linear correlation between adjustment and time since diagnosis supports the notion of varying adjustment over time, the post hoc analysis of current age and adjustment produced conflicting results. The findings produced no evidence of peaks and troughs in adjustment at known times of transition. This is somewhat confusing, as the literature that supports a fluid and flexible model of adjustment also suggests that particular developmental milestones are linked with a predictable drop in levels of parent adjustment, as parents are reminded of the differences between expectations and experiences e.g. going to primary school, onset of adolescence, leaving secondary school, 21st birthdays (Wikler *et al*. 1981). The results of the current study appear to indicate that there are no specific time points within a child's developmental trajectory that are associated with poorer parental adjustment. However, it is important to note that the current study of current child age and parent adjustment is cross-sectional. Longitudinal studies would allow for within-subjects comparisons, which would provide richer detail about a parent's adjustment process over time and at different developmental milestones.

Hypothsis 3: Informational support to understand their child's needs will account for a significant proportion of the variance in parental psychological adjustment

Overall, the findings from the current study indicate that informational support to understand a child's needs is not predictive of parental adjustment, however there are a number of factors that prevent meaningful interpretation of this result. We still know very little about the factors that prevent a family accessing support, or the circumstances under which supports can be best utilised. This is an area of interest for the future, as the evidence base for parent interventions is developing, and the extent to which these evidence based supports can be accessed will be important.

Limitations and directions for future research

Participants were recruited to the research regardless of gender. A disadvantage of including parents of both genders is that the results do not allow for comment on differential adjustment processes between gender. Past research has shown adjustment processes to be different for male and female parents (Heller *et al*. 1997; Saloviita *et al*. 2003). Despite this, the numbers recruited to this study indicate that excluding one gender from the recruitment process would have jeopardised sample size to an extent that effect sizes could have failed to reach the calculated level. Further research would benefit from examination of any differences in acceptance and adjustment between genders.

The number of years that parents completed in full time education was used as a proxy for socio-economic status (SES) in this research design. This design is consistent with previous research in the field (e.g. Gerstein *et al.,* 2009; Hastings *et al.* 2002; Lloyd & Hastings 2009; Trute *et al.* 2005), however it is recognised that

there are other more reliable measures of SES e.g. home postcodes. Previous research in this field that used home postcode data as a proxy for SES found correlations between family deprivation and parental stress, while parental years in education was not found to correlate with any of the outcome variables (Lloyd & Hastings 2008; MacDonald e*t al.* 2010). It is therefore possible that including home postcode data in our analysis would have produced a significant effect of SES on parental adjustment.

In our initial analyses, differences in the adjustment variables were found between parents whose children attended different schools and also in parents of children in different diagnostic groups. While these factors were controlled for in subsequent analysis, the findings cannot be commented upon further in this study, due to small sample sizes in each group. It will likely be of interest to explore the possibility that parents of children with different diagnoses have different adjustment experiences in future research.

A difficulty in conducting research in this field is defining the concept of adjustment. Factors considered under the umbrella of 'adjustment' in the literature include parent attributions (Armstrong & Dagnan 2011), personality (Glidden & Schoolcraft 2003), hope (Lloyd & Hastings 2009b), parent satisfaction (Dukmak 2009), sense of competence (Hill & Rose 2009), and self esteem (Hassal *et al.* 2005). This variation makes comparisons within the literature problematic. The current study used a number of outcome measures to quantify adjustment. Some, such as the HADS (Zigmond & Snaith 1983) have been used repeatedly within the field, whereas

others such as the wellbeing scale (WEMWBS: Tennant *et al.* 2007) and the satisfaction with life scale (SWLS: Diener *et al.* 1985) are relatively new to the field. While this gives opportunity for the consideration of new definitions of adjustment, there is recognition that expansion of the term 'adjustment' has implications for conclusions being drawn from the literature.

A potential limitation in this study is the use of self-report measures. This has largely been the method of choice for gathering information within this field of research, however there are methodological difficulties in this approach, in that self report methods of data gathering can lead to bias. In the field of interventions to support parents of children with LD/ ASD, there are examples of conflicting parent reports and clinician observations in intervention outcomes (e.g. Roberts *et al.* 2011). There has also been research to suggest that maternal reports of a child's challenging behaviour can be biased by the mother's emotional state (Najman *et al.* 2001). Including objective methods of data gathering may increase the validity of the results by reducing bias.

The current study has highlighted a need for more accurate measures of assessing the impact of informational support on parental adjustment. The level of optimum informational support, and the method through which this is best accessed remain unclear. Further research may also focus on the quality of support available, and on the accessibility of this.

Further longitudinal support is needed in order to ascertain the process of adjustment over time. This would allow for development of theoretical models of

adjustment that take time into account, which may then provide a framework for optimum service provision to support these parents. While early intervention is generally thought to be of use to parents, findings in the literature suggest that professionals may over-estimate early maladjustment (Wikler *et al.* 1981). A robust understanding of the factors that influence parent adjustment over time is needed in order to ensure the needs of parents are met when appropriate.

The field would also benefit from continued development of specific outcome measures. This study has highlighted the apparently multi-faceted concept of acceptance, and the research appears to show signs of recognising the process of adjusting to raising a child with LD/ ASD as a unique process. Validation studies of more specific outcome measures will aid in defining the process of parent adjustment, and the factors associated with this in relation to parenting a child with LD/ ASD. Use of specific measures will also allow for future comment on the nature of acceptance as a complex and multi-faceted concept, and the specific role that this can play in parental adjustment to having a child with LD/ ASD.

Conclusions

This study has provided evidence to support the notion that acceptance predicts significant variance in parent's adjustment to having a child with LD/ ASD. This finding may have implications for the development of appropriate interventions to support parents in the adjustment process. The study also explored the impact of informational support offered to parents to help them to understand their child's condition and needs. Further research into the nature and impact of acceptance

and informational support may assist in theoretical framework development, which will ultimately enhance our understanding of the interventions that can best support this population of parents throughout the process of adjustment.

6.7. References

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APPENDICES

A. Information sheet to parents

B. Demographic questionnaire

C. Ethical consent (School of Health in Social Sciences)

D. Author guidelines (for systematic review and journal article)

Appendix A

Information sheet to parents

Dear Parent/ Guardian,

I am a Trainee Clinical Psychologist and I am conducting a piece of research in North and South Lanarkshire that will form my final year thesis project at the University of Edinburgh. I am interested in how having a child with additional support needs (ASNs) affects parents' well being and how parents cope with their child's additional needs. Finding out about these factors is important, as it may help local services to develop in line with the needs of families. In order to research this, I have asked all of the schools for children and young people with ASNs within North and South Lanarkshire to distribute this pack of questionnaires to the parents of all pupils.

It will take around 15 minutes to complete all of the enclosed questionnaires. You are under no obligation to complete them, and the information that I am asking for is totally anonymous – neither you nor your child can be identified from your answers. If you would like to participate, please complete the questionnaires, seal them in the envelope that they came in, and return them to your child's school, where I will collect them. **Please return questionnaires before schools close for Easter Holidays**. Two sets of questionnaires are enclosed, to allow both parents - or any other key carers - to participate.

The questionnaires ask a bit about family life, and your stress and mood levels. If you feel that things are getting on top of you, and you would like some advice or support to deal with these issues, please contact your GP, who can help to direct you to services that could support you.

If you would like more information about my study, or have any questions about the research, please feel free to contact me on 01698 244 320.

Thank you for taking the time to help me with my study,

Yours sincerely,

Laura Rolfe
Trainee Clinical Psychologist

Supervised by
Dr Magnus Cormack
Consultant Clinical Psychologist

Dr David Gillanders
Doctoral Programme in Clinical Psychology
University of Edinburgh

Appendix B

Demographics Questionnaire

Questionnaire for Parents

About your child…

- Your child's date of birth __/__/__

- Have you been given a formal diagnosis by your child's doctor, Paediatrician or other NHS professional?

  Yes ☐ No ☐

- If yes, what formal diagnosis have you been given? (please tick all that apply)

  Autism/ Asperger Syndrome ☐
  Learning Disability ☐
  Global Developmental Delay ☐
  Down Syndrome ☐
  Cerebral Palsy ☐
  Epilepsy ☐
  Other (please specify)……..

- If no formal diagnosis, please describe your child's needs. Give any labels that have been mentioned

  ……

- Date of diagnosis (or, if no confirmed diagnosis, date that you and professionals became confident that your child had developmental difficulties. This could be the date on which it was decided that he/ she should access specialist services or specialist school) – please be as specific as possible __/__/__

- What level of Learning Disability have you been told that your child has? (please circle)Mild Moderate Severe Profound Unsure

About you (please circle)

- Are you… Mother Father Other carer (please specify)……

- Marital status: single married divorced/ separated

- Age:

- Age at which you left full time education :

Support from services

- Families get support from a number of places. We are interested in the types of formal support that you have received from services such as CAMHS, Paediatricians, Social Work, Speech & Language etc. **We are interested in whether you have been offered specific support to understand your child's needs.** Please tick the box below that applies to you

  No input ☐
  One-off appointment at assessment ☐
  Follow up appointments after assessment ☐

- Have you ever accessed any resources to help you understand your child's needs e.g. leaflets, diagnosis-specific guidance, websites etc.?

  ☐ Yes ☐ No

If you have any additional comments, please use the box below

Thank you for taking the time to complete these questionnaires

Appendix C
School of Health in Social Science Ethical Approval

RE: Level 1 for review - Laura Rolfe

Ethel Quayle [Ethel.Quayle@ed.ac.uk]

Sent: 30 December 2011 15:46

To: Rolfe Laura (NHS LANARKSHIRE)

Cc: KELLY Evelyn [Evelyn.A.Kelly@ed.ac.uk]

Dear Laura,
Thank you for submitting the additional information. I am satisfied that the proposal meets the requirements for a Level One submission and does not present any complex ethical issues.

Best wishes,

Ethel

Appendix D

Author guidelines for submission to Journal of Applied Research in Intellectual Disabilities (JARID)

5. MANUSCRIPT TYPES ACCEPTED

Original Articles, Review Articles, Brief Reports, Book Reviews and ***Letters to the Editor*** are accepted. ***Theoretical Papers*** are also considered provided the implications for therapeutic action or enhancing quality of life are clear. Both quantitative and qualitative methodologies are welcomed. Articles are accepted for publication only at the discretion of the Editor. Articles should not exceed 7000 words. Brief Reports should not normally exceed 2000 words. Submissions for the Letters to the Editor section should be no more than 750 words in length.

6. MANUSCRIPT FORMAT AND STRUCTURE

6.1 Format

Language: The language of publication is English. Authors for whom English is a second language must have their manuscript professionally edited by an English speaking person before submission to make sure the English is of high quality. It is preferred that manuscripts are professionally edited. A list of independent suppliers of editing services can be found at http://authorservices.wiley.com/bauthor/english_language.asp. All services are paid for and arranged by the author, and use of one of these services does not guarantee acceptance or preference for publication.

6.2 Structure

All manuscripts submitted to the *Journal of Applied Research in Intellectual Disabilities* should include:

Cover Page: A cover page should contain only the title, thereby facilitating anonymous reviewing. The authors' details should be supplied on a separate page and the author for correspondence should be identified clearly, along with full contact details, including e-mail address.
Running Title: A short title of not more than fifty characters, including spaces, should be provided.
Keywords: Up to six key words to aid indexing should also be provided.
Main Text: All papers should be divided into a structured abstract (150 words) and the main text with appropriate sub headings. A structured abstract should be given at the beginning of each article, incorporating the following headings: Background, Materials and Methods, Results, Conclusions. These should outline the questions investigated, the design, essential findings and main conclusions of the study. The text should then proceed through sections of Introduction, Materials and Methods, Results and Discussion, and finally Tables. Figures should be submitted as a separate file.
Style: Manuscripts should be formatted with a wide margin and double spaced. Include all parts of the text of the paper in a single file, but do not embed figures. Please note the following points which will help us to process your manuscript successfully:
-Include all figure legends, and tables with their legends if available.

-Do not use the carriage return (enter) at the end of lines within a paragraph.
-Turn the hyphenation option off.
-In the cover email, specify any special characters used to represent non-keyboard characters.
-Take care not to use l (ell) for 1 (one), O (capital o) for 0 (zero) or ß (German esszett) for (beta).
-Use a tab, not spaces, to separate data points in tables.
-If you use a table editor function, ensure that each data point is contained within a unique cell, i.e. do not use carriage returns within cells.

Spelling should conform to *The Concise Oxford Dictionary of Current English* and units of measurements, symbols and abbreviations with those in *Units, Symbols and Abbreviations* (1977) published and supplied by the Royal Society of Medicine, 1 Wimpole Street, London W1M 8AE. This specifies the use of S.I. units.

6.3 References

The reference list should be in alphabetic order thus:
-Emerson E. (1995) *Challenging Behaviour: Analysis and Intervention in People with Learning Disabilities*. Cambridge University Press, Cambridge.
-McGill P. & Toogood A. (1993) Organising community placements. In: *Severe Learning Disabilities and Challenging Behaviours: Designing High Quality Services* (Eds E. Emerson, P. McGill & J. Mansell), pp. 232-259. Chapman and Hall, London.
-Qureshi H. & Alborz A. (1992) Epidemiology of challenging behaviour. *Mental Handicap Research* 5, 130-145

Journal titles should be in full. References in text with more than two authors should be abbreviated to (Brown *et al*. 1977). Authors are responsible for the accuracy of their references.

We recommend the use of a tool such as EndNote or Reference Manager for reference management and formatting.
EndNote reference styles can be searched for here:
http://www.endnote.com/support/enstyles.asp
Reference Manager reference styles can be searched for here:
http://www.refman.com/support/rmstyles.asp

The Editor and Publisher recommend that citation of online published papers and other material should be done via a DOI (digital object identifier), which all reputable online published material should have - see www.doi.org/ for more information. If an author cites anything which does not have a DOI they run the risk of the cited material not being traceable.

6.4 Tables, Figures and Figure Legends

Tables should include only essential data. Each table must be typewritten on a separate sheet and should be numbered consecutively with Arabic numerals, e.g. Table 1, and given a short caption.

Figures should be referred to in the text as Figures using Arabic numbers, e.g. Fig.1, Fig.2 etc, in order of appearance. Figures should be clearly labelled with the name of the first author, and the appropriate number. Each figure should have a separate legend; these should be grouped on a separate page at the end of the manuscript. All symbols and abbreviations should be clearly explained. In the full-text online edition of the journal, figure legends may be truncated in abbreviated links to the full screen version. Therefore, the first 100 characters of any legend should inform the reader of key aspects of the figure.

Appendix E

Assumptions for diagnostic group and outcome variable (square root transformation)

Variable	Diagnostic group	Skew (z-score)	Kurtosis (z-score)	Kolmogorov-Smirnov (*p*=.05)	Levene's statistic (*p*=.05)
Parent age	LD	1.41	0.22	.082 (.200)	1.384
	ASD	1.13	0.35	.076 (.200)	(.253)
	LD+ASD	0.01	1.11	.224 (.017)	
Parent years in education	LD	6.01	5.05	.240 (<.001)	.394 (.675)
	ASD	5.22	2.47	.271 (<.001)	
	LD+ASD	3.78	2.63	.272 (<.001)	
Child age	LD	1.72	1.48	.148 (.031)	1.635
	ASD	0.03	1.89	.155 (.002)	(.197)
	LD+ASD	1.33	1.34	.222 (.019)	
Time since diagnosis	LD	0.69	1.67	.090 (.200)	1.255
	ASD	0.68	1.04	.074 (.200)	(.297)
	LD+ASD	0.93	0.75	.188 (.092)	
AAQ-IDP	LD	1.67	1.06	.105 (.200)	2.176
	ASD	1.71	1.23	.131 (.020)	(.116)
	LD+ASD	0.03	1.52	.175 (.152)	
HADS anxiety	LD	1.33	1.54	.134 (.047)	2.164
	ASD	1.26	1.23	.152 (.003)	(.117)
	LD+ASD	0.71	0.89	.127 (.200)	
HADS depression	LD	1.04	0.38	.100 (.200)	1.803
	ASD	0.21	1.25	.122 (.039)	(.167)
	LD+ASD	1.19	0.39	.101 (.200)	
PGS	LD	1.22	0.14	.158 (.008)	.881 (.416)
	ASD	1.48	0.88	.087 (.200)	
	LD+ASD	0.61	0.94	.179 (.131)	
PFP subscale of QRS	LD	0.57	1.83	.115 (.167)	.185 (.831)
	ASD	1.42	1.74	.121 (.043)	
	LD+ASD	1.64	0.01	.193 (.075)	
SDQ	LD	1.77	0.27	.120 (.114)	.346 (.708)
	ASD	0.17	0.64	.079 (.200)	
	LD+ASD	1.42	1.55	.122 (.200)	
SWLS	LD	1.78	0.75	.157 (.008)	1.357
	ASD	1.53	1.72	.112 (.085)	(.255)
	LD+ASD	1.11	0.02	.193 (.075)	
WEMWBS	LD	0.64	0.14	.069 (.200)	2.556
	ASD	1.63	0.53	.076 (.200)	(.080)
	LD+ASD	1.59	0.27	.134 (.200)	

Appendix F

ANOVA for diagnostic group and outcome variables

Outcome variable	Diagnostic group	*N*	Mean	*SD*	Sum of squares	*df*	Mean square	*F*	Sig.
Parent age	LD	92	6.43	.533	1.223	2	.612	2.057	.131
	ASD	88	6.32	.556					
	LD+ASD	36	6.55	.544					
	Total	216	6.40	.548					
Parent years in education	LD	73	3.50	.330	.114	2	.057	.554	.576
	ASD	81	3.51	.321					
	LD+ASD	30	3.44	.294					
	Total	184	3.49	.320					
Child age	LD	92	11.94	1.968	26.700	2	13.350	3.707	.026
	ASD	88	11.25	1.715					
	LD+ASD	36	12.02	2.128					
	Total	216	11.67	1.921					
Time since diagnosis	LD	66	10.03	2.947	183.134	2	91.567	11.870	.000
	ASD	66	7.87	2.566					
	LD+ASD	24	10.16	2.854					
	Total	156	9.14	2.965					
AAQ-IDP	LD	92	4.37	1.111	5.215	2	2.607	2.147	.119
	ASD	88	4.44	1.032					
	LD+ASD	36	4.82	1.234					
	Total	216	4.48	1.107					
HADS anxiety	LD	92	2.61	1.026	1.593	2	.797	.787	.457
	ASD	88	2.79	.910					
	LD+ASD	36	2.76	1.167					
	Total	216	2.71	1.005					
HADS depression	LD	92	2.01	.962	7.641	2	3.820	3.513	.032
	ASD	88	2.03	1.086					
	LD+ASD	36	2.52	1.123					
	Total	216	2.10	1.055					
PGS	LD	92	3.54	.612	5.139	2	2.569	6.178	.001
	ASD	88	3.55	.632					
	LD+ASD	36	3.96	.587					
	Total	216	3.61	.634					
PFP subscale of QRS	LD	92	1.78	1.118	11.785	2	5.892	4.445	.013
	ASD	88	2.00	1.150					
	LD+ASD	36	2.46	1.232					
	Total	216	1.99	1.170					
SDQ	LD	92	3.98	.769	17.763	2	8.881	16.357	.000
	ASD	88	4.43	.696					
	LD+ASD	36	4.76	.752					
	Total	216	4.30	.789					
SWLS	LD	92	4.84	.836	6.121	2	5.892	4.445	.013
	ASD	88	4.68	.849					
	LD+ASD	36	4.35	1.032					

	Total	216	4.69	.888					
WEMWBS	LD	92	6.80	.808	4.295	2	2.148	3.150	.045
	ASD	88	6.72	.772					
	LD+ASD	36	6.39	.977					
	Total	216	6.70	.834					

Appendix G

Assumptions analysis for school and outcome variables (square root transformation)

Variable	School	Skew (z-score)	Kurtosis (z-score)	Kolmogorov-Smirnov (*p*=.05)	Levene's statistic (*p*=.05)
Parent age	A	0.94	-0.84	.338 (.063)	1.401 (.155)
	B	0.55	-1.42	.274 (.200)	
	C	-0.36	-0.99	.226 (.200)	
	D	-1.63	1.06	.232 (.200)	
	E	-0.97	0.60	.110 (.200)	
	F	-0.60	-0.13	.235 (.200)	
	G	0.68	0.23	.211 (.200)	
	H	0.84	-0.94	.308 (.200)	
	I	1.16	0.12	.425 (.003)	
	J	1.35	0.25	.348 (.200)	
	K	-1.53	1.16	.163 (.200)	
	L	-1.08	-0.63	.225 (.200)	
	M	-0.08	-0.16	.200 (.200)	
	N	0.92	0.55	.129 (.200)	
	O	-0.50	-0.72	.293 (.200)	
Parent years in education	A	1.02	-0.65	.212 (.200)	1.415 (.151)
	B	0.54	-0.33	.276 (.029)	
	C	-1.09	-0.05	.284 (.034)	
	D	0.09	-1.48	.276 (.114)	
	E	1.60	1.54	.225 (.001)	
	F	1.51	1.53	.379 (.018)	
	G	1.12	1.89	.381 (.001)	
	H	1.08	1.47	.347 (.001)	
	I	0.31	0.68	.273 (.182)	
	J	0.61	-0.94	.177 (.200)	
	K	1.75	1.44	.28 (.132)	
	L	1.93	1.07	.291 (.001)	
	M	1.69	1.66	.385 (.001)	
	N	1.87	0.57	.293 (.009)	
	O	0.03	-1.42	.261 (.001)	
Child age	A	-1.19	-0.16	.307 (.139)	5.922 (.001)
	B	-0.75	-0.84	.205 (.200)	
	C	0.86	-0.87	.240 (.200)	
	D	0.39	-0.25	.184 (.200)	
	E	0.42	0.79	.175 (.078)	
	F	0.41	0.31	.304 (.143)	
	G	1.18	-0.72	.206 (.200)	
	H	0.41	0.31	.148 (.200)	
	I	0.95	0.52	.290 (.200)	
	J	-1.13	0.36	.291 (.193)	
	K	1.13	0.78	.278 (.200)	
	L	1.04	0.51	.147 (.200)	

	M	0.34	-1.50	.267 (.200)	
	N	-0.56	0.45	.230 (.200)	
	O	1.35	-0.77	.196 (.065)	
Time since diagnosis	A	-0.47	0.90	.283 (.200)	1.415 (.164)
	B	-1.64	1.25	.268 (.200)	
	C	-0.08	-0.66	.186 (.200)	
	D	0.98	0.31	.186 (.200)	
	E	-1.66	0.09	.128 (.200)	
	F	-1.63	1.07	.317 (.200)	
	G	-1.35	1.15	.288 (.081)	
	H	-0.91	-0.20	.154 (.200)	
	I	0.99	0.47	.286 (.200)	
	J	0.60	0.42	.216 (.200)	
	K	-1.39	0.64	.258 (.200)	
	L	0.29	0.36	.171 (.200)	
	M	-0.27	-0.42	.167 (.200)	
	N	-0.46	-0.90	.211 (.200)	
	O	-1.43	0.16	.147 (.200)	
AAQ-IDP	A	0.19	0.11	.232 (.200)	1.237 (.251)
	B	0.68	-0.40	.222 (.200)	
	C	0.97	-0.94	.350 (.021)	
	D	1.42	1.25	.327 (.087)	
	E	-0.73	-1.02	.110 (.200)	
	F	0.74	-0.69	.287 (.200)	
	G	0.88	-0.21	.187 (.200)	
	H	0.39	1.00	.154 (.200)	
	I	1.25	-1.17	.323 (.087)	
	J	1.35	0.92	.204 (.200)	
	K	0.16	-1.38	.311 (.066)	
	L	1.31	0.93	.176 (.200)	
	M	0.30	-1.05	.186 (.200)	
	N	-0.30	-1.45	.253 (.200)	
	O	0.94	0.67	.130 (.200)	
HADS anxiety	A	0.93	0.85	.225 (.200)	.966 (.490)
	B	-1.88	1.75	.373 (.022)	
	C	1.42	1.11	.260 (.200)	
	D	1.95	1.65	.299 (.165)	
	E	0.70	-0.55	.137 (.200)	
	F	-1.73	1.30	.364 (.138)	
	G	-1.38	-0.27	.208 (.200)	
	H	-0.40	-0.11	.163 (.200)	
	I	-0.77	-0.42	.253 (.200)	
	J	1.31	1.00	.251 (.200)	
	K	-1.82	1.46	.404 (.200)	
	L	0.47	-0.97	.188 (.200)	
	M	-0.15	1.55	.287 (.134)	
	N	-1.32	0.70	.208 (.200)	
	O	-1.51	0.50	.143 (.200)	
HADS	A	-0.44	0.68	.171 (.200)	.626 (.842)

depression	B	-0.73	-1.35	.315 (.117)	
	C	-0.03	-0.27	.183 (.200)	
	D	0.31	-1.05	.206 (.200)	
	E	-0.49	-0.81	.134 (.200)	
	F	-1.47	-0.79	.276 (.200)	
	G	-0.02	0.79	.128 (.200)	
	H	-0.78	-0.31	.111 (.200)	
	I	-0.69	-0.23	.243 (.200)	
	J	0.17	-0.75	.242 (.200)	
	K	0.24	-0.55	.179 (.200)	
	L	0.25	-1.07	.170 (.200)	
	M	0.50	-0.06	.175 (.200)	
	N	-0.09	-1.40	.238 (.200)	
	O	0.17	-0.33	.155 (.200)	
PGS	A	1.31	0.44	.222 (.200)	1.618
	B	0.45	-0.43	.234 (.200)	(.077)
	C	0.47	0.25	.196 (.200)	
	D	-0.87	-0.60	.269 (.200)	
	E	0.39	0.07	.120 (.200)	
	F	-1.15	0.85	.298 (.200)	
	G	-0.90	-0.06	.167 (.200)	
	H	0.74	0.21	.134 (.200)	
	I	0.93	0.58	.237 (.200)	
	J	-0.62	-0.70	.217 (.200)	
	K	1.16	-0.26	.212 (.200)	
	L	0.50	1.69	.251 (.074)	
	M	-0.62	-0.29	.232 (.200)	
	N	0.62	0.39	.230 (.200)	
	O	-1.03	-0.60	.196 (.066)	
PFP subscale of QRS	A	0.13	-0.72	.239 (.200)	2.218
	B	-1.90	1.77	.328 (.084)	(.008)
	C	0.46	-0.07	.298 (.103)	
	D	-1.16	-0.34	.310 (.131)	
	E	0.02	-1.30	.118 (.200)	
	F	-0.69	0.75	.307 (.200)	
	G	-1.15	0.21	.238 (.155)	
	H	-1.15	0.21	.125 (.200)	
	I	1.16	0.34	.309 (.200)	
	J	0.90	-1.06	.362 (.031)	
	K	-0.69	-0.46	.288 (.200)	
	L	-0.77	-0.14	.163 (.200)	
	M	-1.05	0.65	.203 (.200)	
	N	-0.72	-0.06	.216 (.200)	
	O	-1.05	-1.33	.157 (.200)	
SDQ	A	-0.66	-0.54	.217 (.200)	1.950
	B	-1.72	1.37	.260 (.200)	(.023)
	C	-0.52	-0.08	.143 (.200)	
	D	0.08	-0.90	.221 (.200)	
	E	-0.70	-0.44	.089 (.200)	

	F	-1.42	0.96	.315 (.200)	
	G	0.51	0.41	.184 (.200)	
	H	0.44	-0.96	.182 (.194)	
	I	0.02	-0.90	.175 (.200)	
	J	-0.39	-0.43	.164 (.200)	
	K	0.75	-0.23	.245 (.200)	
	L	0.14	-0.31	.116 (.200)	
	M	-0.78	-0.03	.153 (.200)	
	N	0.83	-0.37	.198 (.200)	
	O	0.39	0.01	.077 (.200)	
SWLS	A	-0.66	-1.55	.324 (0.57)	1.537
	B	1.12	0.55	.211 (.200)	(.101)
	C	0.41	-1.28	.203 (.200)	
	D	-1.93	1.70	.310 (.130)	
	E	-0.60	1.18	.122 (.200)	
	F	-0.06	-1.15	.305 (.200)	
	G	0.01	-1.25	.191 (.200)	
	H	-0.30	-0.98	.158 (.200)	
	I	1.41	-0.29	.365 (.200)	
	J	-1.46	-0.90	.223 (.200)	
	K	0.36	0.03	.173 (.200)	
	L	-0.88	-0.24	.180 (.200)	
	M	-0.45	-0.97	.215 (.200)	
	N	-1.47	0.80	.216 (.200)	
	O	-1.63	0.17	.168 (.192)	
WEMWBS	A	-0.22	-1.22	.213 (.200)	2.038
	B	0.41	-0.07	.213 (.200)	(.017)
	C	0.48	-1.05	.216 (.200)	
	D	-1.34	0.59	.227 (.200)	
	E	-0.45	-0.12	.133 (.200)	
	F	1.84	1.42	.389 (.200)	
	G	0.86	0.96	.168 (.200)	
	H	-0.65	-0.50	.191 (.147)	
	I	0.71	-0.34	.243 (.200)	
	J	1.18	0.43	.203 (.200)	
	K	-1.82	1.46	.422 (.200)	
	L	0.03	-1.37	.202 (.200)	
	M	1.01	0.36	.165 (.200)	
	N	1.27	0.80	.219 (.200)	
	O	-1.36	0.18	.157 (.200)	

Appendix H

ANOVA for school and outcome variable

Outcome variable	School	*N*	Mean	*SD*	Sum of squares	*df*	Mean square	*F*	Sig.
Parent age	A	8	6.14	.453	11.508	14	.822	3.094	.001
	B	12	6.15	.695					
	C	10	6.16	.382					
	D	7	6.66	.314					
	E	39	6.67	.479					
	F	6	5.77	.303					
	G	15	6.44	.404					
	H	23	6.16	.561					
	I	8	5.89	.689					
	J	7	6.15	.308					
	K	6	6.70	.433					
	L	17	6.32	.588					
	M	14	6.32	.674					
	N	22	6.70	.328					
	O	22	6.56	.486					
	Total	216	6.40	.548					
Parent years in education	A	8	3.63	.408	2.076	14	.148	1.726	.055
	B	10	3.26	.102					
	C	9	3.54	.283					
	D	7	3.69	.299					
	E	36	3.56	.352					
	F	5	3.43	.469					
	G	13	3.41	.198					
	H	20	3.49	.370					
	I	6	3.28	.201					
	J	6	3.63	.362					
	K	6	3.42	.310					
	L	15	3.60	.409					
	M	12	3.41	.287					
	N	11	3.51	.285					
	O	20	3.40	.166					
	Total	184	3.49	.320					
Child age	A	8	12.88	.306	423.166	14	30.226	44.670 (Welch)	.001
	B	12	10.29	1.184					
	C	10	9.89	1.31					
	D	7	13.36	.799					
	E	39	12.69	1.890					
	F	6	10.37	.239					
	G	15	13.54	.760					
	H	23	10.35	.849					
	I	8	10.62	1.481					
	J	7	10.61	.633					
	K	6	12.90	.472					

	L	17	9.92	1.882					
	M	14	9.91	1.425					
	N	22	12.04	1.708					
	O	22	13.44	.716					
	Total	216	11.67	1.921					
Time since diagnosis	A	5	8.08		424.459	14	30.319	5.500	.001
	B	7	7.27	2.558					
	C	8	6.34	1.446					
	D	6	8.08	2.293					
	E	25	11.06	3.591					
	F	4	7.96	2.896					
	G	11	11.96	.798					
	H	17	7.29	1.899					
	I	6	10.12	1.949					
	J	6	7.46	1.645					
	K	5	8.34	1.383					
	L	13	8.66	2.389					
	M	7	7.52	2.151					
	N	14	9.89	2.285					
	O	22	10.08	3.043					
	Total	156	9.14	2.965					
AAQ-IDP	A	8	4.35	1.090	23.437	14	1.150	1.527	.104
	B	12	3.82	.823					
	C	10	4.92	1.224					
	D	7	4.75	1.004					
	E	39	4.45	1.111					
	F	6	3.96	1.591					
	G	15	4.68	1.228					
	H	23	4.60	.958					
	I	8	4.25	1.032					
	J	7	3.67	.778					
	K	6	4.66	1.025					
	L	17	4.69	1.336					
	M	14	5.09	1.324					
	N	22	4.16	1.053					
	O	22	4.58	.804					
	Total	216	4.48	1.107					
HADS anxiety	A	8	2.95	.838	26.821	14	1.916	2.046	.062
	B	12	2.52	1.054					
	C	10	3.08	.748					
	D	7	2.75	.888					
	E	39	2.77	.870					
	F	6	1.44	1.133					
	G	15	2.97	.964					
	H	23	2.97	.735					
	I	8	3.07	1.033					
	J	7	1.91	.733					
	K	6	2.94	1.013					
	L	17	2.79	.998					

	M	14	2.97	.974					
	N	22	2.22	1.129					
	O	22	2.62	1.238					
	Total	216	2.71	1.005					
HADS depression	A	8	1.77	1.052	36.934	14	2.638	2.651	.001
	B	12	1.88	1.100					
	C	10	2.68	.987					
	D	7	2.00	.802					
	E	39	2.09	.998					
	F	6	1.19	.947					
	G	15	2.44	1.022					
	H	23	2.31	1.041					
	I	8	2.22	.692					
	J	7	.73	.732					
	K	6	2.22	1.034					
	L	17	2.42	.936					
	M	14	2.72	.718					
	N	22	1.68	.992					
	O	22	2.10	1.274					
	Total	216	2.10	1.055					
PGS	A	8	3.19	.710	7.126	14	.509	1.293	.214
	B	12	3.41	.410					
	C	10	3.64	.596					
	D	7	3.77	.581					
	E	39	3.53	.732					
	F	6	3.86	.755					
	G	15	3.54	.427					
	H	23	3.22	.507					
	I	8	3.67	.367					
	J	7	3.91	.937					
	K	6	3.72	.774					
	L	17	3.80	.796					
	M	14	3.50	.588					
	N	22	3.52	.574					
	O	22	3.61	.559					
	Total	216	3.76	.634					
PFP subscale of QRS	A	8	1.64	1.363	45.820	14	3.273	4.656 (Welch)	.001
	B	12	1.39	1.285					
	C	10	2.34	1.400					
	D	7	2.67	.421					
	E	39	1.95	1.117					
	F	6	1.04	.548					
	G	15	2.58	.758					
	H	23	2.38	.929					
	I	8	1.95	.641					
	J	7	.63	.838					
	K	6	2.69	1.093					
	L	17	2.43	1.235					
	M	14	2.12	1.204					

	N	22	1.60	1.133					
	O	22	1.78	1.343					
	Total	216	1.99	1.170					
SDQ	A	8	4.45	.755	16.103	14	1.150	2.210 (Welch)	.022
	B	12	4.32	.411					
	C	10	4.74	.393					
	D	7	5.14	.801					
	E	39	4.06	.936					
	F	6	4.24	.584					
	G	15	4.22	.589					
	H	23	4.59	.489					
	I	8	4.01	.760					
	J	7	3.87	.684					
	K	6	4.67	1.210					
	L	17	4.26	.978					
	M	14	4.55	.879					
	N	22	4.05	.743					
	O	22	4.20	.756					
	Total	216	4.30	.789					
SWLS	A	8	4.96	.894	19.314	14	1.380	1.834	.036
	B	12	4.78	.782					
	C	10	4.08	.924					
	D	7	4.39	.566					
	E	39	4.64	.941					
	F	6	5.66	.267					
	G	15	4.21	.999					
	H	23	4.73	.818					
	I	8	5.05	.719					
	J	7	5.25	.695					
	K	6	4.31	.898					
	L	17	4.60	.966					
	M	14	4.82	.795					
	N	22	4.90	.719					
	O	22	4.63	.993					
	Total	216	4.69	.888					
WEMWBS	A	8	7.07	.740	20.443	14	1.460	3.247 (Welch)	.001
	B	12	6.96	.541					
	C	10	6.12	.727					
	D	7	6.75	.414					
	E	39	6.69	.875					
	F	6	7.68	.538					
	G	15	6.30	.818					
	H	23	6.72	.585					
	I	8	6.74	.657					
	J	7	7.42	.463					
	K	6	6.24	.764					
	L	17	6.45	.953					
	M	14	6.50	.843					
	N	22	6.89	.615					

	O	22	6.61	1.180					
	Total	216	6.70	.834					